Effectiveness of Personal Planning for Residents Re-entering the Community during the Facility Initiative in Ontario

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Dedication

To my Mother and Father, who taught me that each of God's creatures deserve kindness and respect.

To Michelle. My teacher, my mentor, and my friend. Thank you for helping me to find all that I came looking for.

To Ross. Your influential and dedicated work as both clinician and researcher is weaved throughout this entire document. You inspired me very step of the way. Thank you.

Abstract

This paper reports on the relocation of people with intellectual disabilities (ID) from large-scale provincially run institutions that took place in Ontario as part of the Facility Initiative. Three case studies were examined in order to report on this process as experienced by those who lived and worked through it. Specifically, the planning process conducted by the Ministry of Community and Social Services (MCSS) to assist each person with his/her transition to community living was examined using the current standard of practice in person- centered planning approaches. Effectiveness was evaluated as the ability to apply a person-centered approach across settings and people, as well as what factors facilitated or hindered its application. Results show that, in general, the personal plans do not appear to reflect the pre-transition *experience* of the person. Also, the transitional planning process did not appear person-centered nor facilitate further person-centered planning in the community.

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I must acknowledge the special individuals, and their families, who participated in this study and allowed us to learn so much from all that they have accomplished. These people bravely shared with us some of the most intimate spaces and times of their lives. Their stories are shared here with respect and gratitude. It is my hope that we have truly captured the uniqueness and essence of each individual.

I would also like to thank all of the direct-care staff, administrators, and planners for giving us so much of their time. It is important to acknowledge the work of the direct-care staff members who are entirely devoted to supporting each individual in achieving their unique goals (C, you are an angel).

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Introduction

The first reports of the closure of large, segregated, psychiatric and mental health facilities can be found in the literature as far back as the1950s when Australia began to relocate residents to community dwellings. The origin of the deinstitutionalization movement has been attributed to Denmark's 1959 *Mental Retardation Act*, which granted "the mentally retarded civil rights in nearly all respects" (Bank-Mikkelsen, 1969, p. 1). Variations of this process are now in place in the United Kingdom, the United States, Australia, and Canada (Doessel, 2009).

In Canada, the deinstitutionalization process for people with intellectual disabilities (ID) has been supported by the federal government since the early 1980s (Lemay, 2009). However, the Facility Initiative in Ontario began sometime earlier, in the 1970s. In 1987 the Ontario provincial government made a firm commitment to close each of the sixteen residential institutions by 2012 (Ontario Government, 2004). The process evolved over the next few decades with a series of closures and then in 2004 the Ontario provincial government announced that it would close the remaining three institutions by 2009. The government committed $276 million to strengthen community supports and service including $70 million to create new residential options for people leaving the institutions (http://www.news.ontario.ca/mcss/en/2009/03/closing-institutions-for-people-with-a-developmental-disability.html). In March of 2009 the remaining three institutions closed their doors permanently. In its four-decade history, the Facility Initiative in Ontario prompted the return of over 7,000 people to the community (Lemay, 2009).

Although this process is now complete in Ontario there remain many more individuals with ID and other diagnoses living in large-scale facilities in Canada and

elsewhere. In 2010 the Chairman of the National Association for the Dually Diagnosed (NADD) United States Policy Committee reported that in the United States there was a "significant slowing of the trend of movement of people out of state facilities" (McNelis, p.18, 2010). In fact, the chairperson reported that in 2007 although 2,637 individuals were discharged an additional 2,128 individuals were admitted (McNelis, 2010). Thus although policy and practice are moving towards community living for individuals with ID, the ID field has yet to reverse the reliance on institutionalization as the response to meeting the needs of individuals who present challenges to community placement.

One emerging trend that has received considerable acceptance in the field of human services is the concept of person-centered planning. By examining the unique needs of each individual and by planning with and for the individual, it is anticipated that community living supports can be developed to accommodate and support a range of individual needs and reduce the reliance on alternative living situations, such as institutionalization (D. Griffiths, personal communication July 22, 2010). In Ontario, the Services and Support to Promote the Inclusion of Persons with Developmental Disabilities Act (2008) outlined that person-directed planning services be available to adults with ID to help him/her identify his/her goals and access services to help facilitate his/her personal life plans (http://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/DS_legislationeng_web.pdf). In many states in the United States the law now mandates the application of person-centered planning approaches in community-living planning for people with ID (Holburn, 2002). As such practices are being written into law and accepted by policy-makers and clinicians as best-practice it is essential that more research

be conducted to establish whether person-centered planning approaches also meet the requirements of evidence-based practice.

In the literature review that follows, the author will review the history of deinstitutionalization in Ontario and the shifting role of planning from traditional to person-centered planning in the transition of individuals from the institution to the community. The person-centered approach to planning will be discussed with special reference to key features of the approach (Medora & Ledger, 2005), agency culture as it applies to the implementation of a person-centered approach (2002), policy direction in Ontario (Individualized Funding Coalition of Ontario [IFCO], 2007), and MCSS Guidelines (2005). The practice and empirical research for person-centered planning will be explored, leading to the implications for shift for deinstitutionalization and our current research questions.

Literature Review

This section will review the history of large-scale institutions in Ontario including the deinstitutionalization process with a specific focus on person-centered approaches to transitional and community-living planning.

A Review of the History of Institutions for People with ID in Ontario

The first institution opened in Ontario in January 1841 as part of the Old York Jail in Toronto. At that time, there were no preparatory measures or guidelines for supporting people with ID and healhcare provisions for their care did not exits. People with various disabilities were 'housed' in prisons, often along with unwed mothers, and the elderly who had no family members to care for them. Access to medical services for people with ID was scarce. Life expectancy was short and infant mortality was high (Oullette-Kuntz

et al., 2005). The facility was soon deemed inadequate and the residence was relocated to an old unoccupied wing of the Parliament Buildings in Toronto. The facility was moved once again when the Provincial Lunatic Asylum was opened in 1850 in Toronto. This site is known today as the Queen Street location of the Centre for Addiction and Mental Health. In 1859 the Government opened a modified hotel in Orillia known as the Convalescent Lunatic Asylum, a satellite program affiliated with the Toronto Asylum. Again, there were few provisions in place for the care and treatment provided to residents. Following the rapid degradation and closure of the Orillia institution, residents were moved to the Idiot Branch of an asylum in London, Ontario.

Meanwhile, the Orillia institution was being reconditioned, as the demand for institutional space was high. In 1876 it reopened as the first training hospital for children with ID in the country, called a Hospital School. Thirty-five people with ID from the London Asylum and Ontario correctional facilities were the first residents of the new facility in Orillia. The institution was expanded three times from 1885 to 1915 due to over-crowding. In 1915 it was home to 1,200 residents (Williston, 1971). At its peak resident population reached 2,600. It was most recently known as the Huronia Regional Centre (http://www.accesson.ca/en/dshistory/firstInstitution/huronia.aspx). The need for specialized, versus generic, care for people with ID for had been realized and policy-makers believed that special institutions could provide more consistent medical care. Intellectual disability was seen as a medical condition requiring constant medical care. The original intent was to provide this care for young children diagnosed with ID, with a goal of rehabilitation (Ouellette-Kuntz et al., 2005).

The early 1900s saw the repeated closure and re-openings of training schools from political pressure due to high costs and ineffective teaching. A shift in focus from providing training for people with ID to reducing the costs of running an institution came into place in 1906 with the appointment of a Provincial Inspector. Residents were then made to work on farms constructed on facility grounds to reduce costs (Williston, 1971).

The construction of large-scale institutions continued with the opening of the Rideau Regional Centre in 1951 near Smiths Falls. It was originally called the Ontario Hospital School and built as an eight thousand square foot institution. It grew to include 50 two-storey interconnected building. Facilities also expanded to include an eight hundred-seat auditorium, gymnasium, and indoor swimming pool. It also held industrial-style laundry and food preparation facilities (IBI Group, 2008). Twenty years after opening, in 1971, it was home to 2,070 residents (http://www.accesson.ca/en/dshistory/firstInstitution/rideau.aspx).

In 1947 the first classroom for children with an intelligent quotient below fifty was established in Kirkland Lake (Griffiths et al., 2009).

In 1953 the Ontario Association for Retarded Children (OARC) (known today as Community Living Ontario) was created by four mothers of school-aged children with ID in recognition of a need for better services and concern for their children living in a provincially run institution (http://www.class.on.ca/Applications/History.pdf). The OARC continued to grow with the amalgamation of other parents groups. According to Anglin and Braaten (1978) parents organized to lobby the provincial government for funding for classes and schools that member groups had. Families refuted the prevailing

status quo of a lifetime of intuitional care for people with ID as the one-and-only solution (Anglin & Braaten, 1978).

By 1960, after years of hardship created out of the Depression and Second World War, the number of residents in provincial institutions had doubled. The Huronia Regional Centre had a resident population of 2,800. The Rideau Regional Centre had 2,600 residents. The facilities were entirely self-sufficient and closed to the public, including family members (Williston, 1971).

In 1961 the Southwestern Regional Centre was opened in Chatham- Kent, modeled after the Rideau Regional Centre. It was the last large-scale provincial institution built in Ontario.

A turning point in the care of people with ID in Ontario came in 1964 with the creation of the first ever inter-departmental committee devoted to the services provided to people with ID. Many government branches were involved including the Departments of Education, Corrections, and Welfare. Specialized training for the care of people living in the institutions was refocused and a shift was made to individualize programming (Williston, 1971).

In 1967 an article written by the Honourable Dr. Matthew Dymond entitled Services for Children with Mental and Emotional Disorders advocated for vast reform of the practice for supporting people with ID in Ontario. Dr. Dymond's involvement in this issue was sparked by a column written in the Toronto Star by Pierre Burton in 1960 describing the his visit to the intuition in Orillia, following up on various accounts he had heard about the conditions at the institution (Griffiths, Owen, Hamelin, Feldman, Condillac, & Frijters, 2009), Burton's (1960) article described conditions of

overcrowding and disrepair noting peeling paint and "enormous gaping holes", roof's that leaked, and holes in the floor patched with plywood (Simmons, p.vx, 1982 as cited in Griffiths et al., 2009). Dr. Dymond's 1967 article became know as the "Blueprint" for a collective approach to service development that arose in Ontario and directed governmental departments to work with other professional, parent, and volunteer groups (Griffiths et al., 2009).

A major shift in deinstitutionalization process began in Ontario in the mid-1970s when The Developmental Services Act was passed, creating a new path for the services for people with ID in Ontario. The focus was on community services and responsibilities were shifted to the MCSS (http://www.mcss.gov.on.ca/en/dshistory/community/1970s.aspx). This involved looking at different living arrangements for people within the institution such as smaller living units. It also involved moving people out of the institutions wherever possible. In 1982, programs such as Homes for Special Care were created. It provided home-like settings for those still requiring total care. These often resembled nursing-style homes (Williston, 1971). Although the deinstitutionalization process that led to the closure of all sixteen provincial institutions in 2009 continued to progress (See Table 1: Government-operated institutions for people with a developmental disability), led by social movements and continued shifts in political philosophy and power (Landesman & Butterfield, 1987) in 1981 there remained 6, 561 residents in schedule 1 and schedule 2 institutions in Ontario.

The shift in philosophy and uprising of social advocacy and parent groups was influenced heavily by the normalization movement originating in Scandinavia and later brought to the United States by Wolfensberger (Nirje, 1985). The principle of

normalization "means making available to all people with disabilities patterns of life and conditions of everyday living which are as close to the regular circumstances and ways of life or society" (Nirje, 1985, p.65). From the initial downsizing of the institutions that saw people grouped and moved into smaller hospital-like units, to community group homes, to the individualized placement of former residents during the Facility Initiative, the goal of normalization (Nirje, 1985) has been more closely realized for these residents today. People with ID are living more independently with a right to choice and control over supports and services they receive.

Although the universal goal of deinstitutionalization for all people with ID remains a debated topic in the field of health and social services (Griffiths, 1984; Lemay, 2009) it seems appropriate, now that the remaining facilities are closed, to change our focus from this debate. Specifically, it would seem impossible to argue, at this point, that the construction of large scale, generic, housing units for people with ID should ever be revisited. Numerous published studies have demonstrated positive outcomes for people who have moved back to the community. For example, Kim, Larson, and Lakin (2001) published a review of the literature on research conducted in the United States from 1980 to 1998 and found that for people with ID adaptive behaviours increased and challenging behaviours generally decreased in community setting as compared to institutional settings. "There is now no serious alternative to the principles that services should be tailored to individual needs, circumstances, and wants" (Mansell & Beadle-Brown, 2003, p.3). It follows then, that the argument for the place of intuitions in (or out of) society hardly seems viable anymore. What is important is an examination of the *effects* of the deinstitutionalization process on the lives of the people who have experienced. This will

provide valuable information that will contribute to improved outcomes for others who still remain in institutions.

A Review of Transitional Planning: Traditional and Person-Centered Approaches

Historically, the process of moving people from institutions to community residences involved placing the individual in a group home where he/she was most likely to fit within existing structures. This is typically referred to as service planning or traditional planning (Mercer, 2003). Service plans were developed for the individual by a professional who determined who should live with whom and where. In this type of planning the professional has control over the direction of the person's life and tries to find a way to make the person happy within exiting support systems. Plans and planning meetings follow a standard format and base their quality and success on standardized outcomes (Mercer, 2003). That is, desired outcomes would be agency specific and apply generally to every individual as a measure of successful planning. The same outcome measures were applied for all service users. For example, if the staff to service user ratio was smaller in his/ her new environment, regardless of other variables, planning could be seen as successful. More recently, as in the case of the Facility Initiative in Ontario, planning for individuals with ID has shifted from traditional individual or service planning to person-centered approaches to planning as theses approaches have become central to disability services (Holburn, 2002).

Person-centered planning (PCP) refers to planning specifically focused on the goals and wishes of the individual. It emerged in the mid 1980s as a result of a need for a more comprehensive understanding of the lived experiences of people with ID. It continued to grow with the progression of the deinstitutionalization and normalization

movements and the realization that integrated community living was a real possibility for all people with disabilities. Generally, all person-centered approaches share a common "emphasis on the principles of self-advocacy and attention to personal strengths and capacities rather than on inadequacies" (Rudkin & Rowe, 1999, p. 364) with goals to "reduce social isolation and segregation, establish friendships, increase opportunities to engage in preferred activities, develop competence, and promote respect" (Holburn, 2002, p.250). For the remainder of this paper the term 'person-centered planning' is used to refer to the general approach and not specific styles that have emerged such as Essential Lifestyle Planning (Smull & Burke Harrison, 1992) or Whole Life Planning (Butterworth, 1993).

Person-centered approaches differ from traditional or individual planning in that there is no professional authority or deficit orientation in the planning process. Instead, there is only a facilitator who guides the meetings, maintains records, and helps the person shape services to meet his/her vision. The facilitator role is filled by a neutral party independent of service delivery and is ideally chosen by the individual (Mercer, 2003). This characteristic is echoed in The Signature Paper (2007) written by the IFCO. The Paper (2007) was written to outline a policy framework needed to ensure the implementation of the transformed developmental service system in this province. Promoting citizenship means the empowerment of all citizens and according to the IFCO (2007) independent planning, or facilitation, is proposed to contribute to this outcome. Several studies have shown that better quality of life outcomes are achieved when *independent* planners *assist* each person and members of her/his support network to develop goals, community interests, social supports, and specific personalized plans

(Holburn, 2002). The process revolves around the final goal of creating a picture of a lifestyle that the individual desires (Holburn, 1997).

Another difference between traditional planning and PCP is that in traditional planning direct-care staff or family members are generally asked about the person's preferences and what he/she would choose in defined situations. In a person-centered approach the individual directs all planning and is consulted in all planning areas. However, planning with individuals with more profound ID makes this process more difficult. Communication and behaviour challenges require adaptations to this process. Therefore, as Reid and Green report (2002), the default strategy is to follow traditional planning strategies for decision making. That is, staff, and, when possible, family members, are consulted to provide information on perceived preference and choices of the individual. This practice is not reflected in the literature however, as Reid and Green (2002) report several studies have shown that preferences identified by others do not accurately reflect the preferences of the individual when assessed using systematic preference assessments. "Investigations have repeatedly shown that caregivers of people with highly significant disabilities typically have opinions that are not accurate representations of the true preferences of these individuals" (Reid & Green, 2002, p.186).

Although there are different forms of PCP, Medora and Ledger (2005), drawing on Sanderson (2002), have identified key features common of all PCP approaches. First, the person is at the centre of everything that is planned. Whenever possible, directives and choices come directly from the individual him/herself. At times, the person is supported in making the decisions. In all cases, the person is consulted in every decision. Second, family members and friends of the person support the person in planning. This

differs from being substitute decision makers. It means that those the person identifies as important to him/her will help the person achieve his/her choices, advocate for what the person needs and wants, and help him/her make changes when necessary. Third, the plan reflects what is important to the person and his/her strengths. As Mercer (2003) suggests, typically people by what their specialty skill sets are, not what they cannot do. Yet people with ID are always defined and described by their deficits. In the case of person-centered approaches the focus is not on skill deficits but on the person's strengths and how those strengths contribute to actualizing dreams and goals. Fourth, the plan results in specific actions that are biased towards inclusion of the person in the immediate and larger community. Finally, the plan results in an ongoing process of listening, learning, and future action. Therefore the original plan is just the beginning step towards lifelong planning for full citizenship by inclusion in all areas of typical daily living. No matter the variation of PCP implemented, these guidelines should be met. When followed, these guidelines facilitate creativity and resourcefulness amongst planning teams and help people to attain their personal goals. However, in many cases, person-centered approaches are applied superficially and important decisions are still made for the person by people who must work to sustain a system (Mercer, 2003). Having these general guidelines to key features that apply to all person-centered models allows one to evaluate quickly the degree of person-centeredness in individual cases.

The process of maintaining the ongoing development of the plan in large part becomes the responsibility of the supporting community agency and others who support the individual. Therefore, a plan can be written as person-centered but not be followed or implemented by the supporting community agency. In Sanderson's (2002) review of a

team's implementation of Essential Lifestyle Planning (ELP) (Smull & Burke-Harrsion, 1992) for two individuals with profound ID, the aim of the study was "to explore critical aspects of implementing a style of PCP within a complex organizational context" (p. 100). For one individual, the planning meetings took place at a local pub's special function room. It was a location that also had an outdoor garden that the individual could wander in if he chose to leave the meeting. Meetings were held in the morning and then everyone ate lunch together. Sanderson (2002) reports that people who attended these planning meetings remarked with surprise that, "Derek stayed at the meeting and was apparently happy, as he always became restless and distressed at previous meetings" (p.106). To embed a person-centered approach to planning into a team's culture Sanderson (2002) focused on incorporating ELP into existing team processes. For example, person-centered approaches were introduced into job supervision, team meetings, and team days so they could become part of the work culture. Under job supervision, the team leader worked with staff to review how they were doing individually at implementing the plans. Team meetings were restructured to include the celebration of efforts that were successful in terms of implementation and identification of barriers. Team members talked about what they learned about the individuals and if amendments to plans were needed based on that. During team days, staff focused on learning more about the individuals to increase their understanding of the person and also his/her community. A focus was placed on what else they could try to expand the opportunities of these individuals.

Sanderson (2002) defines a person-centered *team* as one that "sees it's purpose as supporting people to achieve their desired lifestyle as part of their local community, and

its members are characterized by their willingness to continually listen and learn and their high value on personal commitment and relationships with the people whom they support" (Sanderson, p.117). Sanderson found that the implementation of written plans was limited to the extent that this type of planning was integrated within the team's culture and processes. "The research concluded that simply having a plan is no enough to ensure that people's lives continue to change" (Sanderson, 2002, p.97). Agency culture is as important in actualizing person-centered goals.

Assessing the Application of Person Centered Planning: Quality of Life Outcomes in the Community

Improved quality of life is perhaps the most important goal of the deinstitutionalization process through PCP. Wigham et al. (2008) reported on quality of life outcomes for sixty-five people with ID in England. The most commonly reported benefit of PCP for this group was an increase in activity and opportunity. The second most common benefit reported was that the person felt better about him/herself, was happier, and had more self-esteem. The authors speculated "this must surely be the ultimate aim of those seeking to improve the quality of life of people with intellectual disabilities" (Wigham et al., 2008, p. 144). Holburn et al. (2004) reported better outcomes for a PCP group compared to a matched group receiving individual service planning. Outcome measures included quality of life indicators such as choice-making, daily activities, relationships, and autonomy (Holburn et al., 2004). These outcome measures can therefore be reflective of the implementation of PCP, as compared to traditional planning, in the community.

Person-Centered Planning and Intervention Research

Person-centered planning is typically disregarded as an intervention particularly because it is difficult to operationalize and hard to replicate; its very nature is to resist the standardization of procedures (Holburn, personal communication, June 23, 2010). Therefore, intervention research, where a criterion for a sound study is adherence to the processes as defined, is challenging and therefore limited in this area (Holburn & Vietze, 2002). Another difficulty in the area of PCP research is the problem of assessment. In clinical practice it is not uncommon to promote goals such as increased quality of life and autonomy but it is not common for the researcher to operationalize goals this way. As such, assessment tools must be narrow enough to allow for precise definition and measurement but with flexibility to encompass individualized outcomes (Holburn & Vietze 2002). Holburn and Vietze (2002) conclude, "because of these challenges, we believe that PCP is the most difficult approach to research that the field of developmental disabilities has confronted" (pp. 15).

A Review of the Evidence Base for Person-Centered Planning

Rudkin and Rowe (1999) completed the first systematic review of the evidence base for PCP for persons with an ID. After completing an exhaustive electronic and manual search the authors concluded that no randomized controlled trials of PCP for adults with an ID had been published within the scientific literature. What is more, despite the hundreds of studies identified through their search "only five contain[ed] any recognizable outcome data, while the rest [were] descriptions of the process, overviews or present[ed] purely qualitative information" (Rudkin & Rowe, 1999, p.367). The authors concluded that there is no statistically significant evidence to support the use of any form PCP or the use of lifestyle planning in general in the ID population.

With limited empirical investigation there is little research to support the adoption of this approach as public policy. In 2000, Kinsella suggested that there was still almost no evidence of the effectiveness of PCP approaches compared to other approaches. According to Lemay (2009), this is particularly true in Canada, "very little research has been conduced on the deinstitutionalization projects and the impacts and bona fides of such endeavors have not been well documented in Canada" (p.181). Mansell and Beadle-Brown (2004) reported that there is little to no evidence that person-centered approaches benefit people with ID. Felce (2004) commented that, "I tend to agree with Mansell and Beadle-Brown that PCP has a rather weak evidence-base for the centrality of its position in policy" (p.27).

Person-Centered Planning and the Facility Initiative in Ontario

Even without a strong empirical evidence base, person-centered approaches were already being implemented in the province in regions such as Windsor, St. Mary's, and Durham (Lord, n.d) as part of the Facility Initiative. A person-centered approach, by way of the personal plan (herein referred to as 'the plan'), was implemented for all individuals who left the final three facilities to close. This method was formalized in the Guiding Principles (MCSS, 2005); guidelines created to "define how a person leaving a facility [would] move into a setting that can support each individual's needs" (p.1, 2005). The Guidelines highlight flexibility, choice, fairness, inclusion, health, and independence. The process was to involve the individual him/herself, his/her family or advocate, Regional Placement Facilitators (herein refereed to as 'the Facility Planner'), and future supporting community agency. This was the Ministry's guide to engage all participants to work together to build on the strengths their current situation and identify services for the

future. The mandate was for a semi-independent Facility Planner to assist each person returning to the community in developing a personal plan that was tailored to his/her strengths, needs, and preferences (Lord, n.d.). In 2008, The Services and Support to Promote the Inclusion of Persons with Developmental Disabilities Act was passed in Ontario. The Act outlines, among other points, that person-directed planning services be available to adults with ID in Ontario to help him/her identify his/her goals and access services to help facilitate his/her personal life plans (http://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/DS_legislationeng_web.pdf). The Act brought about an important change, announcing that the MCSS had formally added PCP to its list of services for adults with ID. In this case, best-practice was established before evidence-based practice.

The Research-to-Practice Gap

As noted, the effectiveness of person-centered approaches as a strategy has yet to be substantially confirmed by research (Griffiths et al., in progress). Although no randomized controlled studies have provided objective and scientifically robust evidence, the person-centered approach has become accepted as best-practice and extended to a variety of populations. The distinct lack of research focusing on the particular characteristics and issues that may allow for the planning process to be *applied* successfully on a case-by-case basis represents a major gap both within the literature and between research and practice. Holburn (2002) concludes:

> We have not systematically identified the conditions under which person- centered planning is most effective. More specifically, we have not determined which

components, nor do we know which kind of outcomes are more likely to result from the various forms of person-centered planning that presently exist. (p.253).

But as Felce (2004) points out, it would be difficult to contest the logic of these approaches and the necessity of an "approach to knowing people well enough so as to be able to make support arrangements that meet their individual requirements and take account of their preferences and lifestyle choices" (p.27). The relevant question, as he suggests, "is not whether person-centered planning has the potential to improve people's lives but whether policy has identified the conditions under which its widespread implementation would be possible without degradation of the process and its impact" (Felce, 2004, p.27-28).

Quantitative research is necessary to systematically answer questions of causal relationships in a definitive way. Researchers working in the area of person-centered approaches to planning continue efforts to develop such lines of research despite the obstacles mentioned above (Holburn & Vietze, 2002). Qualitative research, on the other hand, can suggest possible relationships for further systematic analyses and identify information that can be analyzed for overall trends or themes without attributing causal relationships (Wagner, 2002). It speaks to individual differences and informs qualitative data. The qualitative nature of the case- study component to this study emphasizes the very human experiences that occurred within the institutions and through the deinstitutionalization process in this province. An in-depth case analysis examining the pre- transitional experience, personal plans, and current experiences for individuals living through the transition process in Ontario within the last four years will provide

information to guide future research, policy, and practice in further deinstitutionalization Facility Initiatives in Canada and abroad.

Research Questions

In 1995 the American Psychological Association published the Template for Developing Guidelines: Interventions for Mental Disorders and Psychological Aspects of Physical Disorders to "assure comprehensive and consistency of practice guidelines" (Nathan & Gorman, 1998, p.20). Of particular relevance to this paper is the distinction made between the efficacy and effectiveness:

> Clinical practice guidelines for behavioural Healthcare [should] be constructed on the basis of two simultaneous considerations or "axes". The first is that guidelines take into consideration a rigorous assessment of scientific evidence with the goal of measuring the efficacy of any given intervention. The second axis specifies that guidelines consider the applicability and feasibility of the intervention in the local setting where it is to be proffered [clinical utility, or effectiveness]. Among the factors that will be considered under this rubric are the generalizability of administering the intervention in various settings, the feasibility of the intervention across patients and settings, and the costs and benefits associated with the administration of the intervention. (American Psychological Association Task Force as cited in Nathan & Gorman, 1998, p.3)

The purpose of this research is to address the research-to-practice gap by examining the effectiveness of the personal plans and planning process for three former residents during the final phase of the Facility Initiative in Ontario. Specifically, effectiveness will be addressed by answering the following:

1. Did the planning process and written personal plan reflect:

    a. The pre-transition experience of the individual

    b. MCSS Guiding Principles (2005)

    c. The characteristics of PCP (Medora & Ledger, 2005)?

2. What characteristics allowed for the planning process to be applied successfully? What characteristics of the process were barriers to implementation?

3. Was PCP observed within the community and what themes are correlated with its presence or absence?

Method

Participants

The three case studies included in this study were completed as part of a larger study commissioned by the MCSS. Three individuals with an ID who were former residents of one of the final three facilities to close in Ontario in 2008-2009 were selected from a larger sample of participants originally recruited by mail from the MCSS. Participants were identified based on their consent to participate in the study, as well as the consent of the agency that was currently supporting them in the community. Finally, participants were selected based on the availability of the agency staff to meet with the first author for data collection purposes. All participants lived in the community while participating in this study. Participants were given pseudonyms; real names were not used.

Margaret is a fifty-six year old woman diagnosed with moderate ID, cataracts, bilateral hearing loss, Kyphoscoliosis, Cellulitus, a heart condition, osteoporosis, and

epilepsy. She was admitted to a Provincial Regional Centre at the age of five years and lived there for fifty years. She now lives in a group home in Southern Ontario.

Heather is a fifty-five year old woman diagnosed with profound ID, asthma, and chronic obstructive pulmonary disease. She was admitted to a Provincial Regional Centre at the age of six years. Heather was a resident of the institution for almost forty-four years. She now lives in South-western Ontario where she shares a home with four women who have ID.

David is a sixty-two year old man diagnosed with profound ID, congenital pectus carinatum (pigeon chest), thoracic kyposis, bipolar mood disorder. He also suffered a stroke six years ago resulting in right- sided weakness and loss of mobility. David was a resident of a Provincial Regional Centre for forty-six years. He was admitted at the age fourteen years. David now lives in a shared suite situated in a retirement residence in Southern Ontario. Each participant lived in a different Provincial Regional Centre prior to his/ her transition. Table 2 summarizes participant information.

Current direct-care staff and agency Administrators for each participant were also interviewed. The Facility Planner who assisted each individual as well as family members were also interviewed where consent was obtained.

Measures

History Questionnaire (Griffiths, 2008).

This tool was designed for this study to create a comprehensive picture of the history and current lifestyle of the individual through extensive file reviews, the plan, naturalistic observations, and interviews (Appendix A). It includes sections on

biomedical, psychiatric, psychological, sociocultural, and behavioural aspects of the individual's history.

InterRAI-ID (Martin, 2006).

The InterRAI- ID (2006) is the most recent of a suite of InterRAI assessments designed for use in healthcare planning. The ID assessment was designed for use with adults over eighteen years of age with ID. It contains the following domains: Identification Information; Intake and Initial History; Education, Employment, and Recreation; Psychological Well-Being and Social Supports; Lifestyle' Environmental Assessment; Communication and Vision; Cognition; Health Conditions; Functional Status; Oral and Nutritional Status; Mood and Behavior; Medications; Service Utilization and Interventions; Diagnostic Information; Assessment Information. It contains three hundred and ninety-one items designed to assess the status of people with ID in areas of life including health service history, behaviour, social support, medication, recreation, and life events, for example. It collects information useful for assessing individual outcomes, evaluating quality of services received, and determining the intensity of services needed. The purpose of the instrument is to screen for a wide range of needs or difficulties of the person as well as to identify strengths and preferences to provide a holistic view of the person. It is designed to be completed within approximately one hour by a trained assessor. The InterRAI-ID (2006) was used by the MCSS to help form the planning process for Ontario's three remaining institutions for persons with ID. Reliability measures found embedded scales to be internally consistent and convergent validity of the embedded scales has been reported by its authors (Martin, Hirdes, Fries, & Smith, 2007).

Quality of Life Instrument Package: Quality of Life Questionnaire-Short Version (University of Toronto Centre for Health Promotion, 1997)**.**

This questionnaire is from an Instrument package that defines quality of life is defined in this model as the "degree to which a person enjoys the important possibilities of his/ her life in three board domains: Being, Becoming, and Belonging" (Raphael, Brown, & Renwick, 1999). The specific instrument used from the package was the Quality of Life- Other Person Questionnaire, designed to be completed by someone who knows the participant well. It consists of nine life domains, each with three concepts, and a total of twenty-seven items. This measure allows for comparisons between the perceived importance of a certain quality of life domain (e.g. community belonging) and the extent to which the person makes his/her own decision and has choice around these domains. Response codes are presented on a 5-point Likert-type scale including '1'-Not at all, '2'- A little, '3'- Some, '4'- Quite a Bit, to '5'- A lot. For example, the first question under the Being domain is "How important to him/her is looking after his/her physical health?" The informant responds by selecting the number (1-5) that best corresponds with his/her perception of the importance of that domain to the individual.

The short version was created to be completed in about half the time of the full version and retain the same key concepts the full version (Raphael, Brown, & Renwick, 1999). Raphael, Brown, and Renwick reported, "for all domains of the Full and Short Versions of the Other Person Questionnaire except Psychological Being, the scores were reliable" (1999). Overall qualities of scores are reliable for both versions. Validity was assed by comparing the Full Version and Short Version scores of 500 participants. Correlations between the two very reported as very high for all domain scores (Raphael,

Brown, Renwick, 1999).

Role-specific Interviews (Griffiths, 2008).

Separate interview forms were created for this study to capture information from a variety of levels.

Direct-care staff interview.

This interview explores the staff's perception of the person's post- transition experience. Questions focus son adaptation, relationships, supports, staffing, and professional services accessed. Questions also focus on the daily lives of the person including activities and community inclusion. Finally, staff answer question regarding how the person has changed since moving into his/ her community residence (Appendix B).

Agency administrative staff interview.

This interview was designed to capture which supports, adaptations, staff training, and challenges the community agency planned for in preparing to support participants throughout and following his/ her transition to the community. Administrators also answered questions on their perception of the written personal plans; if the plan was individualized and captured the persons and his/ her needs (Appendix C).

Facility planners interview.

The interview focuses on which supports, adaptations, and staff training were arranged in preparing to support the individual. Questions are also designed to assess if these variables were sufficiently addressed and in place before the person moved to his/ her community residence. Finally, questions address the written personal plan, family involvement, and lessons to send forward to others (Appendix D).

Family interview.

The Family Interview was designed to capture the family member's perception of how the process was experienced for individual and the family as well as how the person is doing in their current situation. Questions are asked regarding the family's feelings and satisfaction with the transition and current placement of their loved one, aspects of the physical environment, relationships with staff, location, and professional services (Appendix E).

Training

Assessors received training on the InterRAI-ID (2006) at approximately one year and again at three months prior to the data collection. Assessors also took part in a one-day training session on conducting interviews and a review of all measures.

General Procedure

This study represents one part of a larger four-part study that was commissioned by the MCSS to evaluate the impact of the Facility Initiative on the individuals, families, and agencies involved following the closure of the remaining three institutions in Ontario. The general procedures described here were completed within the context of the larger study.

1. Letters of invitation were mailed to nine hundred and seventy-five people with ID who had moved from one of the final institutions to close in Ontario to community residences within five years of the study being commissioned by the MCSS. Letters were also sent to his/her family, and community direct-care staff. The participants first had to give the Project Coordinators consent to contact them through the MCSS invitation.

2. Upon receiving consent to contact, the Project Coordinators contacted the supporting community agency to provide further information on participation activities, the purpose of the study, and set a date for research assistants to visit the individual in his/her home to collect data.
3. Written consent was obtained from the community agency Administrator, direct-care staff, and in one case, a family member of a former resident. Consent was not obtained form the individuals' as they were assumed to be incapable of independent consent (Appendices F, G, H respectively).
4. A comprehensive file review was conducted for each participant. Using the History Questionnaire (2008), a complete account of the participants' history was prepared. The file review included the most recent InterRAI-ID (2006) completed before the facility closure.
5. Two-day home visits were completed in the individual's new home. Home visits with participants varied slightly but generally took place according to the following description. Visits commenced in the morning at the participant's home. First, the researchers were introduced to the participant by direct-care staff and told that the researchers were there to visit him/her. The participant was then observed in his/her home. Participants were observed to engage in activities that were described as typical daily activities. All participants were also observed outside of his/ her home. For Margaret and David, this took place at his/ her regular day program site. For Heather, this took place at a local pub that she regularly frequented. The researchers were visible to the participant during all observation periods. Researchers responded naturally to participant- initiated

interactions and sometimes initiated simple interactions such as commenting on an activity or smiling at the participant. Field notes were taken during observation times.

6. All interviews with direct-care staff and agency Administrators were conducted individually and in-person using the role-specific interviews described above. Two interviewers were present and recoded responses. Where direct-care staff felt it possible and appropriate, the participant was directly included in the interview process meaning that he/she was asked questions directly. This was the case for Heather only; she was asked questions from the InterRAI-ID (2006). Heather was also present while the direct-care staff member responded to interview questions. David was in the same room while the direct-care staff member responded to interview questions but was not immediately present. Margaret was not present during interviews.
7. Following the home visits, the Facility Planner for each participant was identified and contacted by email. An electronic copy of the consent form and Facility Planner Interview (2008) was emailed to the Facility Planner (Appendix I). Facility Planners were interviewed over the telephone.

Research Design

The research design and methodology was defined by the parameters of the larger study and the MCSS. A mixed- methods design was used consisting of both quantitative and qualitative methods of assessment to assess the effectiveness of PCP for all three participants. A case study method was used to inform the quantitative data gathered from the questionnaires. Because the case study involves a more subjective design and

selective sampling, it contrasts to quantitative designs using large numbers and random assignments. However a critical inclusion of the case studies in this overall project allows the researchers to triangulate the individual stories with the quantitative data all within the same study. Each case was reported using direct quotations and sections from field notes and interviews to help the reader get a better understanding of the uniqueness of each participants experiences (Bogdan & Biklen, 1992). Our repeated design of multiple case studies using the same design would allow the researchers to convey to the Ministry a thorough account of all phases of the transitional experience that the quantitative data alone might not produce. This case study approach will be repeated and compared across the all individuals from the larger sample to see if there is replication of findings. In addition, the case studies function to ground the research so we can learn from the stories of individuals in the process of leaving the institutions (Griffiths, 2008).

Data Analysis

A comprehensive picture of each individual's pre-transition experience was written based on information collected from the History Questionnaire (Griffiths, 2008) and file reviews. Post-transition accounts were written based on direct observations of the individual in his/her home and community, multiple interviews with staff and family members, and reviews of agency files. Stake (1995) suggests that there are "two strategic ways that researchers reach new meanings about case studies" (p. 74) these are "through direct interpretation of the individual instance and through aggregation of instances until something can be said of them as a class" (p. 74). In the current study, both strategies were used throughout to inform the results of each research question.

The evidence for the case studies came from several sources: historical institutional archival records, survey instruments, interviews, direct observation, and review of current documentation. The historical archival records and the InterRAI-ID (2006) served to create a pre-picture of the individual prior to transition into the community; Yin (2003, p. 88) refers to this as using "documentary sources to reconstruct reality". Post transition surveys, multiple interviews, direct observations and review of current documentation was used to analyze the information from the various sources to form a picture of the transitional and post transition reality for each individual as described by Patton (1987). In addition, cross-case assertions (i.e. Stake, 2006) were derived by comparing the personal accounts and interviews conducted with direct-care staff and administrators for each participant and across participants to identify areas of convergence. Cross-case assertions were identified as critical observations made by the research assistants or staff, consistent across at least two participants. "Triangulation for a multi-case study serves the same purpose as in a single-case study: to assure that we have the picture as clear and suitably meaningful as we can get it, relatively free from our own biases" (Stake, 2006, p. 77). Stake suggests that triangulation follows "a classical strategy", throughout the field work this means observing if new information is consistent with what is know, and evaluation with each site evidence how new information validates or invalidates an emerging assertion. Erikson (1986) refers to assertions as a form of generalization that occurs as the researcher interprets the data.

Ethical Considerations

All procedures complied with the Tri- Council Policy Statement (TCPS, 1998) and it's Guiding Ethical Principles. Careful consideration was given to protect the

privacy and interests of participants. Participants at every level were informed of the purpose of the study and their role beforehand and informed consent was obtained before data collection began. There were no physical risks to participants. The identification of staff participants remained anonymous in this study. None of the information shared by staff participants was reported to either their employers or to the MCSS outside of its publication here.

Results

Research Question 1: Did the planning process and written personal plan reflect:

a. The pre- transition experience of the individual

b. MCSS Guiding Principles (2005)

c. The characteristics of a person-centered approach (Medora & Ledger, 2005)?

The History Questionnaire (2008) was completed through a thorough review of institution records. Information obtained from the History Questionnaire (2008) was used to create a complete picture of the person's pre-transition experience in the institution. These accounts are presented in the following section. The personal plans for each person are then described. Consistency between the pre-transition experience and personal plan is then reported to answer whether the personal plan reflected the pre-transition experience of the person. Finally, the personal plans and planning process described for each individual was then compared to the MCSS Guiding Principles (2005) and characteristics of PCP as described by Medora and Ledger (2005).

Margaret

Pre-transition experience.

Margaret was born in 1952 in Ontario and is the youngest of three girls. At the age of six-months she was diagnosed with Down's syndrome and later, moderate ID. She was admitted at the age of five years on the recommendation of her physician. It was reported that Margaret suffered frequent respiratory infections as a young child and it became difficult for her parents to provide the medical care she needed at home.

Her parents were reported to be very involved, visiting and calling regularly. Early on in Margaret's files there were many letters written from her mother to the Administrators of the institution inquiring about her health and happiness. Although both parents have passed away, she continues to have a relationship with her sisters.

A summary of Margaret's early experience written by a direct-care staff reports that she was lonely and had a poor appetite. She experienced many ear, chest, nose, and throat infections in the institution. Chronic infections to her right middle ear required surgery to remove a growth near her eardrum. She was routinely reported as generally lethargic. Situations that were reportedly unpleasant to Margaret were those that required excessive physical activity, work, or challenging tasks.

Margaret reportedly liked staff attention, watching TV, applying make-up, and getting her hair done. She participated in some community activities including bowling and swimming. Going to the beach was an enjoyed summer activity where she also liked the arts and crafts booths set up on the beach and going on pontoon boat rides.

Some of these activities enjoyed within the institution included dances, lip-sync performances, and holiday parties. She was also a member of the Red Hat Society and participated in a function each month within the institution. Margaret enjoyed short walks within the buildings and liked to go visit the parlor to say hello to staff, have a

short visit, and a coffee. Admission documents indicate that her family attended a United Church but it was not found within her records whether Margaret attended church or chapel while living in the institution.

It was documented throughout her files that Margaret would steal large amounts of toilet paper and because of this she needed to be monitored in the washroom. If not monitored, she would stuff her pockets and hide toilet paper under her clothes and in her bedroom. She would return it to staff without protest when requested to do so. No formal data or interventions were documented for this behaviour. Other than this behaviour, no reports of challenging behaviour were found. Margaret was reported as a generally happy and compliant woman who was able to communicate what she wanted and generally wanted to participate in all activities.

She participated in habilitative programs over the years such as a kinesiology program to improve cardiopulmonary endurance and fitness, a bi-weekly speech (sign) and hearing group for listening skills and language stimulation, a weekly hearing aid support group, and a weekly geriatric group. When given the choice to attend recreation and leisure programs Margaret would typically choose to go. This often involved a home economics activity. In addition to learning home economics skills in the recreation and leisure group Margaret also participated in a community living skills group where she had training in traffic signs and rules, basic meal preparation, and using small appliances. She also participated in a self-help skills group where she learned to remove her own nail polish. Most recently, before she moved, Margaret was attending a workshop program every afternoon. She took a bus there and back. She was also attending a recreation and

leisure program once a week, swimming twice a week, and a spa program three times a week.

Before moving to the community Margaret lived with five men and one woman. Margaret had her own room with two beds. She previously shared her room with another woman who passed away four years before her transfer. Her room was decorated in stuffed animals, posters, and pictures. Her residence had a dining and living area and direct access to an outside deck. On weekends staff would make home-cooked meals and would take Margaret shopping.

With the announcement of the closures, Margaret's family objected to the province's decision and repeatedly sent letters to the provincial Regional Centre's Administrator denying consent for Margaret to move to the community or to visit potential community agencies. The planning process for Margaret did not begin until two years later. Six months after initial planning contact with the family was made the first planning meeting was held. Two planning meetings and a discharge meeting one month prior to her transition were documented to have occurred. Margaret's transition orientation involved three overnight visits to the new home before the transfer. Each time, institutional staff members accompanied her to the home and stayed in nearby hotels. Family participated in all meetings and approved the final placement the night before she was scheduled to move.

The final document in her institution file was a note written by the Facility Planner on the day Margaret moved into her new home. She reported, Margaret "moved into her new home in (name of town). Paperwork was signed and hugs all around. Margaret was adamant that she was staying there."

Description of the personal plan.

A Facility Planner was assigned to lead the planning process and write Margaret's personal plan. Margaret's planning team consisted of seventeen people including family members, her case manager, appointed Healthcare and behaviour consultants, and facility service providers from various departments including kinesiology, program services, food services, audiologist, and the Facility Planner.

The plan consisted of the following sections: Introduction, Biographical Information, Personal History, Current Situation, Likes and Dislikes, Relationships, Daily Routine, Personal Care, Sleeping Habits, Diet, Mobility and Dexterity, Sensory, Personality and Behaviours, Sexual Expression, Spiritual Involvement, communications, past program involvement future directions, as well as a separate attachment on health and wellness.

The introduction to her plan began with a brief overview of the five-year plan to close the three remaining provincially operated facilities. It stated that each person would receive support from existing community and government services (p. 3). The creation of specialized or individual services to meet individual needs or wishes was not mentioned. The stated intent of her personal plan was to be a "broad vision that [would] set out goals and a projection of the individual's future" (p.3). The purpose was for her family and new support group to use this information to continue to develop ideas on how Margaret may experience new and different aspects of life when she moved from the institution to the community. The focus was to be on developing a community and environment that would be supportive of Margaret's needs and a lifestyle suite to her interests, wishes, and abilities. The introduction closed with the directive that the plan was to evolve over time

as Margaret's needs and choices change and that family and staff should continue to add to the plan. Finally, it was noted that the plan was to follow Margaret as she continues on her life's journey.

The first page listed biographical information including her then current institution address, date of birth, place of birth religion, citizenship, and date of admission.

The Personal History section began with the biographical information listed in the previous section. It discusses her mother's maternity history including information of miscarriages. It also discusses Margaret's birth and labor experienced by her mother. Her mood and eating habits as a baby were explained as well as when she met certain milestones such as sitting up, getting her first tooth, and walking. This section also reported on her abilities at admission; she could feed herself and was partially toilet trained but could not dress herself. The review of her personal history also stated that throughout the years staff had discussions about community placement with her family and that she participated in various programs with the goal of community living but her family never supported her leaving the institution. She has a large family including nieces and nephews; she loved caring for the children when she visited her family.

The Current Situation section began by describing Margaret as a quiet and cooperative woman. It described her length of stay in the institution and listed her diagnoses. It described her relationship with her primary counselor and the families unsettled feelings about the closure. It reported that the family was worried that the community would not be able to support their sister as the institution did in particular were there concerns regarding her health needs

Margaret's Likes and Dislikes were listed as eight bullet points and was one of the least detailed sections of her plan. Her 'likes' were listed as staff attention, eating in restaurants, babies and small children, shopping, showing off mail and gifts received, wearing nice clothes, Christmas, and bowling.

Her relationships were also listed in very few bullet points. It described that she used to spend a week at her family home twice a year until her parents noticed that her enthusiasm about visiting decreased and she would wake in the night and begin packing to return to the institution. She was said to miss her peers, the staff, and her work. After her parents died her siblings visited and called her regularly and frequently sent cards and money.

The section on her typical Daily Routine reviewed the times she woke, ate, bathed, took medication, attended workshop, and went to bed. Margaret would let staff know when she was going to bed.

The section on Diet stated that Margaret was at risk for choking and that she ate a minced meat textured diet in the institution. Her diet was restricted from hard items such as apples or carrot sticks. When liquids are refused, the plan stated that thickeners are to be used. It also stated that she needed someone to stand beside her and continually verbally prompt her to eat. It listed the foods she dislikes and stated that she was able to make food choices.

Under Personality she was described as "loving, caring, and sensitive" (p.10). She appreciated kindness, was upset when people were ill, liked to have fun and be playful, was appreciative of things that were done for her, and was able to develop

relationships with others. She did not like to spend time in her room nor have her belongings touched by others.

No behaviour protocols were listed for Margaret although the Behavior section listed in great detail a single instance of smearing feces many years ago. The plan reported that Margaret does not express herself sexually.

The Spiritual section was not completed.

The Communication report told that Margaret could say what she wanted and when she was not feeling well. It described her as communicating both orally and with sign and gestures. Transition notes indicated that the community agency requested a book of the signs Margaret knew and used but there was no mention of this book in the plan.

Under the Future Directions section there were many subsections that, within a person-centered approach, include the individual himself/herself in the writing process. These subsections included: family wishes, goals and wishes, future care providers, training, and development, things that will enhance/ ensure the quality of Margaret's life, transitional issues, decision making, and things to be purchased. Like the other sections described so far, this section also reflected the voices of institution care providers and her family but Margaret was not personally represented. The directives for this section indicated that Margaret was "not able to be an active participant in the planning of her move… to her new home" (p.14).

Consistency of the plan to her pre-transition experience.

The community agency Administrator and Facility Planner were both interviewed with the role-specific interviews (Griffiths, 2008) described above to learn about how the

person-centered approach was applied to the plan and the planning process for Margaret. When asked how well the planning process reflected a person-centered approach the Administrator reported, "I'm not sure I'd call it person-centered. It was made by watching her in the facility once or twice, so it was skewed. The Facility Planner did the best she could with what she had." From that, the Administrator continued to offer that the plan was very "picky" and that none of the supports were needed in the community to the extent that the plan listed. "According to reports from the institution, she was more high needs". When asked if the plan captured Margaret's needs the Administrator offered that, "the Facility Planner was good. [In the plan] she appeared a very sick woman. It wasn't what we saw." More than the actual plan, it was the Facility Planner who was credited with preparing the receiving agency, "the Facility Planner was excellent." The Administrator noted that the plan lacked a focus on Margaret's "new life" and how they could help her discover new things or what she wanted to discover.

When the Facility Planner was asked if the essential elements as outlined in the plan were ready for Margaret to move into the community and were these items in the plan implemented during the transition, the response was "absolutely." A theme that emerged from both review of the plan and the interview with the Facility Planner was that a main goal of the entire process was to have all the medical supports set-up before Margaret arrived. The researchers continually heard that Margaret's medical team (physician, ear, nose, and throat, and foot care specialists) was arranged before Margaret left the institution. This seemed to be a substantial measure of success to the Facility Planner. When the Facility Planner was asked how person-centered the planning was implemented, the response was, "Did she have an active voice? No. She was not able to

say this is what I wanted to do." The plan reports that she is able to tell what she wants and that her receptive speech is very well developed (p. 13).

An unexpected result of the planning process according to the Administrator and the Facility Planner was that it "bridged the family" (Facility Planner). Margaret's family resisted the closure because they were fearful that she would not survive the transition (p.2). However, it was reported that in working with the Facility Planner the family took charge of the process checking each draft of the plan for approval. The Facility Planner reported that the family held her accountable for every decision made.

After reviewing Margaret's plan and in discussing the planning process with people who were involved, it is clear that the process may not have been person- centered as much as it was an individualized planning process. Based on information obtained through completion of the History Questionnaire (2008) it appears the plan did reflect what Margaret generally did in the institution but not necessarily as she experienced it. That is, it describes her personal history, daily routines, behaviour profile and diet in great detail but little is reported on relationships and her personal experience. Margaret was not asked about these things. Therefore, from a clinical perspective, the plan represents Margaret's life; from a person-centered approach, it does not. It also follows a deficiency orientation. The focus of the plan was on ensuring that all the medical supports were in place and meeting the family's requirements. The plan had very detailed information of her past in the institution. It did include one recommendation that she be given the opportunity to try new or different activities, even if only a few times. Goals were described as, "the goals of the planning team" (p. 15).

Margaret's family declined an interview.

Heather

Pre-transition experience.

Heather was born in 1954 in Southwestern Ontario. She lived at her family home as one of five children until she was three years old when she was admitted to the Ontario Provincial Regional Centre in 1961 or 1963 (inconsistently reported in admission records). Her sibling was also a resident at the Centre but had passed away shortly after Heather was admitted. Her family remained involved in her life; her mother was the main family contact person. After her mother died family contact stopped and the whereabouts of her father and other family members are unknown. This communication with her family stopped in the late 1980s. A final letter found in her files written from Heather's caseworker to her father reported that the case manager approached him regarding community placement for his daughter, which he approved. An exception to this is another sibling, a sister who was admitted to a children's residence at a young age and who lived in a supported community home for some time.

Heather was diagnosed as having profound ID, spastic quadriplegia (the most severe form of cerebral palsy), scoliosis of the upper spine, and hyperlodosis of the lower spine. She was also prone to respiratory infections. Heather had an ovarian cyst removed and a hysterectomy.

Completion of the History Questionnaire (2008) revealed that Heather was not prescribed any regular medications aside from those to help her with asthma and respiratory infections. Non-medicinal strategies to help Heather's posture and breathing included chest physiotherapy and therapeutic rehabilitation for increased gaseous exchange, active coughing, loosen mucous and bronchial discharge. After an

anaphylactic reaction she no longer received influenza vaccinations. Only one major hospitalization related to her respiratory difficulties was recorded. This was for treatment for pulmonary aspirations.

In her earlier years at the institution Heather was trained in various communication styles. Blissymbols were effective to teach her receptive language skills, request making, and choice making. She also learned thirty-three symbols in a picture exchange program. Head nodding and eye movements for 'yes' and 'no', vocalizations, pointing, a call bell, and switches attached to her lap try for communicating choices were also taught effectively. Only nodding, pointing, eye movements, and vocalizations were maintained as communication skills. It was not reported why the picture exchange and Blissymbols were discontinued. The switch communication system on her lap tray was lost and therefore no longer available for use.

Reports inconsistently reported situations that gave Heather difficulty. When she was a young participant in programming activities she was reported to be stubborn and did not like corrective feedback. Others reported that she accepted constructive criticism well.

Reinforcement-based habilitative programs were also implemented to teach Heather to effectively feed herself, put on a t-shirt, and eliminate in a bed pan. She also learned from a colour recognition program and electric wheelchair training. Heather was also a participant in an Applied Technology Program that taught keyboard use and computer activities.

There was a lack of information in her institutional files about her community participation. It was noted that Heather enjoyed movies, dances, sing-a-longs, and

special events within the institution. She also enjoyed fingernail painting, putting on make-up, and being outside. She would choose to listen to songs using her keyboard in the Applied Technology Program. She attended music therapy programs intermittently. Heather also attended church within the institution. Before her mother passed away, Heather would return to her family home for Christmas holidays.

Documents containing notes of transition planning appear in Heather's institution files approximately seven years before she moved to the community. Institutional staff members were able to locate Heather's father and encouraged him to attend planning meetings as he had previously given consent for her to move. Six years later, and two years before Heather moved, the institution began making requests for transition planning information to the community agency that was currently supporting Heather's sister in a nearby city. Heather was known to the agency for some time by then, having visited her sister many times. Two years later Heather moved into the home with her sister. The final note in Heather's file on the transition day reports that Heather appeared excited to be home with her sister and friends.

Description of the personal plan.

Heather's planning team consisted of two support staff, a kinesiology therapist, and residential supervisor in addition to the MCSS appointed Facility Planner. Although encouraged to participate, no family members attended any planning meetings. Heather's plan deviated from the others in its identified purpose and instructions. Specifically, her plan stated, " all of Heather's current and future supporters are encouraged to, over time, add to this document so as to create a living plan which reflects hr current and emerging choices and life directions. The personal plan was requested to assist Heather in her

pending move. The document belongs to Heather and she will take it with her in future changes of residence" (p.1).

Heather's plan was also unique in that the focus, and therefore a majority of the document, was on transitional recommendations with little focus on her past in terms of a medical profile or programming information from many years ago. Although Heather was considered medically fragile (p. 4) sections of her Personal History and Current Life Situation focused on her personality, preferred activities, items of interest, relationships, her sister, and ways she communicated. Her plan was also considerably shorter than the others with only two major sections: Personal Story (current life situation) and Transitional Recommendations (support requirements, maintaining good health, life affirming activities). Two brief sections on who would best support Heather and what she needed for a good life, both written in the first person from her perspective, concluded the seven- page document. Under 'What I Need for a Good Life' the plan listed several points that involve community participation. These included having access to regular check-ups, access to leisure activities, and continued celebration of her spiritual and religious life. Finally, the plan stated, "to have a life rich in friends, in health, in skills, character, and family" (p.7).

Heather's plan highlighted her relationship with her sister, who was already living in the home to which Heather would be moving, and indicated that they both wished to live together. She maintained a relationship with her sister that was supported by the agency where her sister lived. This included visits to the home on weekends over several years. Heather enjoyed these visits and this was interpreted as a wish to move in with her sister. The plan also highlighted that quality of life comes from community and personal

relationships and focused more on these points for transitional recommendations than on medical care. For example, the plan stated that future care providers were encouraged to incorporate meaningful activities into her activity calendar by "sampling new experiences from which to make decisions about favored new ones" (p.4). Also, the goal of meeting new, non- paid friends in the community was highlighted. Non-negotiable Healthcare requirements included a continued cardiopulmonary regime. All necessary medical and deficit information was included but it is embedded among her wishes for her immediate future.

Consistency of the plan to her pre-transition experience.

When compared to the History Questionnaire (2008), the plan reflected Heather's pre-transition experience as it was written by others in her institution files. The plan did not focus on medical or behavioural factors other than that which was present in her institution files; it made recommendations for continued non-medicinal therapeutic regimes for her respiratory function. Mot notably, Heather's plan focused on her wishes for a full and active future with her sister by her side.

When asked if the planning was personalized for Heather the agency Administrator reported that in fact it was but that it was a very clinical report, not enough from the first-person perspective, and that the process was rushed. In this case, he reported that more time was needed for this to reflect a "true community planning process" (Administrator). When asked if the plan captured the person's needs, again, he reported yes, but strictly from a clinical perspective. He added, "in general, all kinds of stuff, not a full picture of the person, not as a person" (Administrator).

The Family and the Facility Planner assigned to work with Heather were not available to be interviewed.

David

Pre-transition experience.

David is an outgoing, often outspoken, man who loves music and people. He was born in Montreal in 1947, the eldest of three children. As an infant he was baptized in the Roman Catholic Church. He was a resident of an institution since 1961, leaving his family home at the age of fourteen years. David has a diagnosis of bipolar mood disorder, profound ID, stasis dermatitis, ulcers, right-sided pleural effusion, and has used a wheelchair since experiencing stroke-like symptoms five years ago.

David's parents felt that it was in his best interest to admit him to the institution for formal care. His father was away from the home for many days at a time due to the nature of his employment. David was described as well nourished and well developed at the time of admission. He was also able to use the toilet, dress, and eat independently.

Throughout the files, David was described as a playful man, liking to tease and be teased. He was helpful towards other residents and always identified a peer on his unit in need of support or interaction. He had a special friend in the institution that he would sit beside and hold her hand. She moved to a community residence in a different region as part of the Facility Initiative. It was said that he would ask for her after she left.

Early intervention focused on psychiatric and behavior management. Habilitative pre-vocational programming taught him matching skills, and number and colour identification. He worked on puzzles and computer matching games and his on task behaviour increased with staff praise. He was reportedly very proud of his work

accomplishments. Before the palliative care plan was put in place, David attended a daily workshop where he completed nut- and –bolt sorting work-boards. He enjoyed sitting outside, dances, socials, walks, bus rides, and wagon rides. In the summer he attended camp where he enjoyed pontoon boat rides.

Since the age of forty years, David was treated with Lithium for Bipolar disorder-rapid cycles with Valporic Acid and Thyroxine for 'behaviours' associated with manic episodes and Clorazepam, Tegretol, and Haldol for exacerbation of 'highs. After experiencing stroke like-symptoms David's vocal speech and mobility were significantly affected. The stroke was also said to have affected his mood. A very outgoing person, David then had difficulty speaking and required a wheelchair for mobility. The medication was also said to have had a significant effect on his mood. He also had a history of upper Gastrointestinal bleeding, recurrent vomiting, anorexia and weightless. He was treated with Lithium for anorexia for many years.

Concurrent with the stroke-like symptoms, David showed episodes of decreased levels of consciousness, ataxia, loss of his ability to walk, and right-sided weakness. This was also reported to have affected his mood significantly, showing symptoms of depression. He also experienced recurrent ulcers for which there was ongoing medication treatment.

After experiencing stroke-like symptoms, David communicated primarily through short sentences and gestures; he experienced a loss in his speaking ability. He continued to understand simple directions.

David presumably experienced difficulty dealing with medical procedures as some physical and mechanical restraints were used. Specific restraints reported include a

papoose board, mouth prop, and physical contact from staff. These were used to prevent any dangerous movements or biting down on instruments during procedures. Oral sedation was also used for some dental procedures.

In terms of day or habilitative programming post stroke-like symptoms, David participated in an exercise program three times per week using parallel bars to regain independent transfer skills and mobility skills. He was scheduled to begin a hydrotherapy program but no reports on his participation were found. Finally, a walking program was also developed. He also continued to participate in biweekly musical and spiritual outreach programs

A yellow caution card flagged in David's files represented an uncommon tendency to be aggressive towards staff and residents. This was noted to occur most specifically when staff needed to support him during toileting routines, dressing, eating, and personal hygiene. Also, he did not like to be touched on his right side. David would sometimes spit or bite staff members during theses routines.

In 2006, approximately two years before David left the institution, he was diagnosed with right-sided pleural effusion (fluid around his lungs). While no definitive testing was conducted at the request of his family, it was thought possible that David had a tumor in his lungs. A palliative care plan was put in place and steps were outlined in the event that David entered the infirmary. His family requested that no aggressive resuscitation or heroic measures be taken in the event that his health deteriorated. The family also made a formal statement that it was their wish for David to live out his life in the institution.

Description of the personal plan.

David's Facility Planner was also assigned by the MCSS. The Facility Planner originally met David and his support staff six months before he moved and again two months later. One additional meeting followed with David and his support team. Therefore, a total of three meetings were recorded to have taken place over a six-month planning period. The Facility Planner only met David twice before the final planning meeting was held. David's team included a nurse, facility support staff, occupational therapist, residential supervisor, dental assistant, dietician, psychometrist, appointed Heath Care and Behaviour Consultant. Although David's sisters were identified as being substitute decision makers they were not identified as being part of his planning team.

The plan consisted of the following sections and subsections: Personal History, Present Situation (likes, dislikes, daily schedule, relationships, spiritual involvement) Health and Wellbeing, Behavior, and Future directions. Under Future Directions the key points identified were New Setting Environment, Day Programs, Financial Arrangements, and Family Involvement. According to the Facility Planner, the institution chose the team members with the exception of the appointed Healthcare and Behavior Consultant.

David's plan contained a very long and detailed report of his medical history going all the way back to the details of his birth. It also contained a long behaviour consultation report for which there is only one instance of noncompliance and aggression documented two years prior to the report date. Non- function based interventions such as psychiatric consultations were recommended as strategies to address challenging behaviour during the transition.

The interview with the agency Administrator revealed that the plan was "extremely" individualized, versus personalized, from her perspective although it did not reflect David's support needs as they saw them in the community. For example, the bathing and eating recommendations did not match his level of need following the transition. The Administrator speculated that the Facility Planner, when writing these recommendations, "likely didn't know the actual day-to-day events and what it really looked like when she suggested [things like] the special tub" (Administrator). The Administrator also credited the plan with helping to guide the preparations of the suite built for David and his co-residents, even though not all the accommodations were required. The Facility Planner also highlighted the "great emphasis on the medical piece" within the plan.

The Facility Planner was asked if she felt that the essential elements of plan were ready and in place for David when he moved. The Administrator responded that they were all in place however the moving date was postponed, as the suite was not ready.

As noted above, approximately sixteen months before David was scheduled to move there was evidence of fluid filling a sac between his lungs. Although no definitive testing was conducted it was suggestive of a lung mass. At that time transition planning ceased for David and he was provided palliative care. One year later David "showed no evidence of deteriorating health" and the pleural effusion had shrunk in size (the plan, p. 9). A lung tumor was no longer considered the cause and transition "planning resumed without the parameter of palliative care" (the plan, p.10).

The plan provided no discussion regarding David's goals or wishes. One comment was made that the community agency was encouraged to help David reconnect with his special friend from the institution.

Consistency of the plan to his pre-transition experience.

David's plan was seventeen pages in length. Seven pages made-up the Health and Wellbeing section. The brief summary of his early medical history appeared sufficient in detail. This included a description of the nature and treatment of his mood disorder. The majority of the section focused on his medical status post-stroke. The most recent information was described in the most detail and accurately reflected information gathered from the History Questionnaire (2008). Although he had a complicated medical history post-stroke the plan did conclude that David was medically stable at the time of writing. However, a common criticism identified from the interviews with the community agency Administrator was that the plan depicted a more fragile, severely disabled, sick, dependent person than they are experienced in supporting him post-transition. The extensive summary of support recommendations came from support staff only and did not include David's personal perspective of supports needed or wanted.

The Behavior section comprised four pages of the document although the data presented, from which recommendations were presumably written, included a single instance of challenging behaviour reported a year prior to the plan being written. The recommendations were topographically based and not reported as functionally related to the challenging behaviours listed: uncooperative, agitation, verbal aggression, and physical aggression. This section did not contain any information on maintaining or

increasing behaviors that were a focus of post-stroke habilitative programs such as the independent transfer skill or upper body motor skills.

David was described as an outgoing person who was able to communicate with staff; this appears inconsistent with the lack of any personal future goals or support choices, even if based on observation.

David's family member reported that the plan as completed to the family's satisfaction commenting that if it were not, they would not have approved it. His/her comments focused primarily on the medical section of the plan and his/she satisfaction with it's accuracy in describing his/her brother former status as medically fragile.

Overall Results

In all cases, the plans were reported by direct-care staff and Administrators as being overly clinical in style and not very useful in helping them to better support the person during and following the transition. According to one Facility Planner, these clinical plans "don't amalgamate well" with the style of planning typically done in the community. As a receiving agency, one Administrator reported that all the "non-negotiables get in place, but then went by the wayside."

On the other hand, the Facility Planners were frequently reported as doing diligent work with what they had to work with by Administrators and family members. In David and Margaret's case, the Facility Planner was also credited with helping to ease the process for the family and prompting their involvement despite their having actively protested the facility closures. In all cases, it was reported that the direct communication with the Facility Planner, rather than the actual plan, provided the most useful information for the community agencies.

None of the participants were directly involved in the planning of their transition despite reports that they are all able of communicating in varying ways. A cornerstone of person-centered approaches is that the individual makes his/her own choices and identifies his/her own preferences.

MCSS Guiding Principles

Based on the reviews presented above, the planning process was assessed according to the MCSS Guiding Principles (2005) to determine which components were included for each participant and where there was variation. Results are presented in Table 3. The analysis revealed that the planning process was individualized rather than person-centered for all three participants. That is, plans were tailored to each individual but the person did not have an active voice. Also, for the most part, the scope was limited to existing services. Heather's plan was the only one that met the following Principles: she was directly involved in the planning process; she had the opportunity and support to make decisions about her life; her wishes on where and with whom she wanted to live were given primary consideration; her decisions about relationships were given primary consideration; support planning was flexible; her wishes were not only balanced with available resources but were not limited to existing services. All three participants' personal planning met the following Principles: planning involved existing processes; he/she moved closer to family members; and specialized supports such as mechanical lifts were provided as required.

Person-Centered Planning-Key Characteristics

The plans for the three individuals were compared a second time, this time to the key characteristics of a person-centered approach according to Medora and Ledger

(2005). Results are presented in Table 4. Table 4 summarizes which principles were fulfilled for each participant. All three participants did have a facilitator assigned to chair their planning process although the Facility Planners were not independent, neutral third parties. None of the participants were consulted consistently throughout the planning process. In fact, in each case, the Facility Planner only met the individual for whom they were writing two or three times. Planning meetings were scheduled around the convenience of institution staff and the Facility Planner and not the individual himself/ herself or even their family members. In Margaret's case, the location prevented a family member from participating. Only Heather's plan is specifically stated and treated as being owned by her.

Research Question 2: What characteristics allowed for the planning process to be applied successfully? What characteristics of the process were barriers to implementation?

One purpose of this study was to address the need identified by Felce (2004) to determine the conditions under which a person-centered approach could be implemented most successfully. This was accomplished by interviewing agency Administrators and Facility Planners to identify factors that were seen as facilitators of and barriers to the implementation process. All the accounts reported are taken from interviews with agency Administrators (Agency Administrative Staff Interview), the Facility Planners (Facility Planner Interview), and family member (Family Interview).

Two characteristics were consistently identified as facilitating the implementation of the plan. The first was the presence of a Healthcare Consultant. This position was appointed and filled by a MCSS chosen person. The Healthcare Consultant assisted in

setting up general physicians and other medical supports in the community. In one case, he/she also advocated on behalf of the individual in requesting a new physician when it was felt that the primary physician was not the best fit for that person. "[Healthcare Consultant] did not like the doctor but we had no control over it. We were working with limited sensitivity and understanding from the doctor and therefore [David] really needed advocating for this" (David's Facility Planner). In that same interview the Facility Planner was asked about lessons he/she wished to send forward to others. David's Facility Planner continued, "[Heath Care Consultant] really mitigated, really important role and not everyone has [a Healthcare Consultant]." The Facility Planner went on to say that the Healthcare Consultant assigned to work with David supports people with ID and that this was a great asset to the team. The agency Administrator supporting David also identified the Healthcare Consultant as a "helpful" support arranged when David moved. In Margaret's case the Healthcare Consultant added pre-transition visits to the general physician with her (Margaret's Facility Planner). When asked about positive factors that facilitated thoughtful planning the Facility Planner assigned to work with Margaret reported that one of the biggest supports provided from the MCSS was "bringing in the Healthcare Consultant early on". The Facility Planner continued that in doing so, all issues to be addressed were identified early on in the process. For the one participant who did not have a medical component within his/her plan written by a Heath Care Consultant, direct-care staff noted that, "some of the medical recommendations from the facility staff was outdated. There was no Regional Health Consultant available in the process at that point" (Direct-care Staff Interview).

The second supporting factor, identified by agency Administrators and a family member, was the commitment of the Facility Planner. The Facility Planners were often described as going well beyond what they were asked to do. Examples include arranging for institution staff to accompany the individual for overnight visits in the community, being an emotional support person for the family, and sometimes having to carry out planning duties in the face of direct opposition from the family. One Administrator described the Facility Planner she worked with using these statements: "good Facility Planner", "did the best she could with what she had", "Facility Planner did a good job bridging the family", "Facility Planner was great", "Facility Planner was excellent and went well beyond what she was asked to do". An example given by an Administrator of going beyond assigned planning duties was arranging overnight visits for the individual with accompanying institution staff. The Administrator shared a story of a family's insistence on having institution staff go with their loved one on pre-transitions overnight visits. He/she recalled that the "supervisor was very heavy handed " and the "staff following her had to sit outside". She continued that this "made the Facility Planner very anxious" and that you could "cut the tension with a knife" but that "the Facility Planner was excellent" in dealing with the expectations of all parties involved. Another Administrator described the case where the Facility Planner did a great job preparing him/her directly but contrasted this with the utility of the actual written plan.

One family member was interviewed and also identified the Facility Planner and her work as a very positive factor in the transition process. The family member interviewed described the Facility Planner as an "angel" and "shining star" saying that the "recommended facility was a good fit" and that during the transition he/she was

"dependable", "a good leader", and "knew what to ask for" on behalf of their family and loved one.

Three characteristics were identified as common barriers to the implementation process. The imposed timeline was a significant barrier reported. For example, one agency Administrator shared that he/she felt that "more time for true community planning process" was needed and that "the end process was rushed". He/she also shared that, "the imposed timelines by the planning team did not allow [him/her] to participate fully". Another Administrator also described "timing" as a challenge. In this case the physical space was not ready on time. A second barrier identified by a Facility Planner was available funding; "I just felt really hampered by the financial part of it, for specialized supports, we had to work hard to get that in place". In response to a question about funding for specialized staff training to support the individual post-transition one Administrator reported that although no specialized training was needed they "would not have been funded for training".

Finally, the families and organized groups against the closure of the institutions were identified as being barriers to the planning process by the Facility Planners. Both David and Margaret's families were not supportive of their move to the community or the closure of the facilities. When asked what factors, if any, hindered the planning process the Facility Planner identified two formally organized groups against the closure as "challenges" but noted that the MCSS "told Facility Planners how to deal and react to that." Both families did however actively participate in the planning process.

Research Question 3. Was a person-centered approach observed within the community and what common assertions are correlated with its presence or absence?

Although PCP is difficult to operationalize definitively, a characteristic of a person-centered plan is that it is a living document. It is intended to be an evolving and continually revised document, changing and growing with the person it represents. It follows then, that the planning process, and the written document that it produces, should not signify the end of the process but rather the beginning point from which future direction are shaped. Therefore, the purpose of this third research question was to assess the continuation of the person-centered approach in the community. Specifically, we asked three questions:

1. Following the transition to the community was planning person-centered?
2. What factors or themes correlate with the continuation of person-centered planning in the community?
3. Did current planning (i.e. goals) grow from the original plan?

First, accounts of the post-transition experience were created for each participant based on direct observation, interviews (Front Line Staff Interview, Agency Administrative Staff interview, and Facility Planner Interview), and file reviews of post-transition file documents where available. What follows are individual accounts of each person's post-transition experience as it relates to PCP in the community.

Margaret

Post-transition.

When we met Margaret she had been living in the community for close to two years. At fifty-seven years old, she had lived in an institution for fifty years. Margaret currently lives with five men with a diagnosis of ID. Her home is located on a quiet and tree-lined residential street. She lives in a small community, one that was carefully

selected by her family on the recommendation of the Facility Planner. Although her medical diagnoses include cataracts, bilateral hearing loss, Kyphoscoliosis, a heart condition (not confirmed in most recent documentation), osteoporosis, and epilepsy, the Direct-care staff report that she is an active person and describe her as "the life of the party."

Margaret attends a general day program with approximately ten other adults. The program consists of light aerobic activity three times per week, lunch as a group although Margaret takes her lunch to a separate table to eat, an afternoon activity such as music or craft making, or sometimes an outing such as bowling. Margaret was observed to be very affectionate and playful with the staff. Although she appeared happy and very comfortable in this environment, minimal interaction with other individuals was seen or prompted by program staff. The day program is located close to the group home and direct-care staff members drive the residents between the two locations. When Margaret returned home from the program on our first day of observation, the direct-care staff noted that she was going to "her office to do some work". The staff indicated that her office was a space set-up for Margaret at the recommendation of institutional staff; the institutional staff members had suggested hat Margaret should have a space set- up for her that is outside of her bedroom yet personal to her. Margaret had 'office space' in her institution ward where she would colour and spend time by herself. She continues to use her new office-space in her new home to do the same kind of activities.

Her room is heavily decorated with pictures and personal items. Consistent with the plan recommendation, Margaret and her family have been able to personalize her room with things she likes: teddy bears, pictures, and gifts. In her room, Margaret also

has a special chest that belonged to a friend who passed away while living in the institution with her. It was reported that this is a special treasure of hers and consistent with recommendations, it is kept in her room.

Margaret is described in many reports as being verbal and uses sign language and gestures to augment her vocal speech. (i.e. InterRAI-ID, 2006), staff interviews, the plan). Specifically, it is reported that she can express when she is not feeling well and what she wants. She is also able to make selections from pictures presented to her. Reports from the Audiologist confirmed that Margaret can and will speak when she has is wearing her hearing aids. According to her plan her receptive language skills are well developed. During our visit, Margaret would initiate interactions bringing us to where she wanted to show us her work while prompting us to look at her artwork and special accessories she was wearing that day. She would also ask staff questions about an item or prompt them to tell her something about it.

Current planning for Margaret is said to be individualized by the agency Administrator supporting her. Every year to year and a half they review her plan and create a visual tool for future direction. This tool functions as a map to guide the team in effectively supporting Margaret. "Family, friends, and people she names look at her goals. Day and residential are looked at separately." Medical follow-ups are not required as often as recommended in the plan because Margaret is not ill as often as she used to be. For example, she has far fewer respiratory (Direct-care staff). She also does not require a minced diet as recommended as she cuts and eats her food independently. Finally, it was suggested in her plan that Margaret would need a walker within a year of

her transition but she no longer requires even physiotherapy and is independently mobile (Administrator).

Heather

Post-transition experience.

We met fifty-five year old Heather in the middle of an early spring heat-spell. When we arrived at her home, she was sitting under the canopy on her backyard patio with her sister. She lifted her head to greet us with a magnificent smile as though she was accustomed and excited to meet new people. This is surely the case for Heather as she had been living in her new home for four years. Heather was one of the first individuals to leave a Provincial Regional Centre after the announcement of the Facility Initiative, after living there for approximately forty-four years. Before moving into the centre in 1961 at the age of six years, Heather lived at home with her family but she had been moved into and out of facilities since a young age. She has a diagnosis of Cerebral Palsy. Staff report that she is always understood and clearly understands things said to her (InterRAI-ID, 2006). Her planning team described, "she is extremely aware of her environment and is responsive to others. She easily communicates with blinking of her eyes and is able to gesture toward others" (the plan). This description of Heather was echoed through multiple staff interviews.

Heather lives with her sister and three other women with ID. While Heather and her sister are enabled through the use of wheelchairs, their housemates are more independent and some work in the community. The agency, and more specifically, the staff, who supported Heather's sister before the Facility Initiative were very encouraging of the sisters' relationship and facilitated the strengthening of this bond as much as

possible. The agency had already begun planning for Heather to join her sister several years in advance building a new home for them in hopes that one day the sisters would live together.

Her home is beautiful. It is modern, spacious, clean, and has a real family home feeling to it. There are pictures of the many road trips they have been on showcased throughout the halls. These trips include vacations at the cottage, to see the opera in Toronto, to the aquarium in Chicago, and the mountains in Tennessee. They even have the bumper stickers on the van to prove it. Every resident's room is decorated to her liking. Each chose the themes, colours, and décor style. Heather and her sister share a large room, each with their own furniture and walk-in closets. Everything is personalized right down to the covers on their beds.

The dining room, living room, and kitchen are all open and easily accessible, even when everyone is home. She has access to the fridge, backyard, and television when she wants.

Heather does not attend a day program but her days are filled with activity and variety. She participates in making the grocery lists, shopping at the market, and making lunch to the extent that these are all things she is involved in and makes choices about. When it is time to rake the leaves or shovel the snow she is asked to join in although she is free to refuse if she prefers not to do these chores. Her monthly calendar is also filled with activities. These are activities in the community including restaurants, pubs, malls, markets, friends' houses, cooking classes, and everyday errands that need to be done. Direct-care staff members also plan theme parties every month including spa days and birthday and holiday celebrations. Heather can have her hair died if she wants to. She

does the things that people who have always lived in the community do; she is an active community member.

David

Post-transition.

When we met sixty-two year old David he was quick to extend his hand and strike up a conversation about whom we were and why we had come to visit. He asked us our names and joked with us. Staff reported that they are usually able to understand David and that with some repetition he typically understands what is being said to him (InterRAI-ID, 2006).

David had been living in the small custom build unit for just over two years. The unit was built within a large assisted living complex for senior citizens to accommodate his potential medical needs. He lives with two other men and one woman. This unit is not reflective of a family-style home and more closely resembles a hospital setting. His family, on the recommendation of the Facility Planner, chose it for David. A few years before the transition process began for David he was diagnosed as potentially having a lung mass (no invasive testing was done) and ordered to receive palliative care. Although this measure of care was removed and his condition had improved and stabilized while still living in the institution, planning for David continued to follow what his needs would have been if he still required that type of care. The Facility Planner reported that the senior's facility was a good fit for David because of these medical needs although he no longer presented with these issues. The Facility Planner also reported that family was content with this option in the sense of planning ahead; the supports would be

there when he needs them. Although current direct-care staff reported that his health continues to improve there are no plans to change his current living situation.

David is a resident of the senior's facility, however he is not well received by the other residents. A petition was signed by the other residents to remove David from the dining hall because he was too loud. Now, he takes the elevator up to the dining hall with staff to get his meals and returns to his unit to eat. He is also not allowed to attend church but he does visit the chapel.

The unit has a fridge and microwave but no formal kitchen. There is a very small living space that seems awkward for two residents who use a wheelchair and one who uses a walker. There is a small bookshelf with some books and puzzles on the far end of the room. David's bedroom is lit with natural light coming in from large windows. He has a special bed with railings, consistent with plan recommendation, for his safety at night.

David attends a music program located in the building next to the senior's facility. He was observed to enjoy the instruments and making song requests, to which the music leader happily obliged. Other individuals attending the day program appeared very happy to see David and some exchanged handshakes and even a hug. David was supportive; congratulating is his friend when shown a picture of the friend's baby nephew. It is often clear that David enjoys his time there so much he does not want to leave. Staff reported that he commonly engages in challenging and sometimes aggressive behaviour when removed from the complex and brought back to his suite (direct-care staff).

Person-Centered Planning in the Community

To assess the degree of person-centeredness in community planning we examined staff responses on several measures. First, the purpose of section M3 of the InterRAI-ID (2006). Sections on Prevention, Service Use, and Intervention- Focus of Supports are designed to capture information regarding the focus of supports that the person has received in the month preceding the assessment date. Responses range from '0'- no service or program of this type, '1'- offered but refused, '2'- not received but scheduled to receive in the next 30 days, '3'- received 8-30 days ago, to'4'- received in the last 7 days. This is a valid method for assessing in what areas of learning and growth the person is receiving support, or, where there appears to be a lack of support. The degree of support being received in the community and whether this matches participant's needs or wishes provides insight into how much these supports match a person- centered approach. For example, if the person identified a goal of being out in the community more frequently, having Community Skills Training in place presumably demonstrates person- centered planning of supports being received (Section M3b, InterRAI-ID, 2006). Response code '1'- offered but refused, can also give insight into potential supports that do not match the client's goals and where further analysis may be warranted. Scores for all three participants are displayed in Table 5.

Table 5 shows that with the exception of sensory stimulation programs for Heather received within the month prior to the assessment and for David within the week prior to the assessment, no training or formal habilitative supports are in place or scheduled to begin for all three participants.

The Quality of Life Questionnaire (1997) allows for comparisons between the perceived importance of a certain quality of life domain (i.e. community belonging) and

the extent to which the person has choice and can change issues around these domains in his/her life. For example, if he/she does not like the food they eat or the people he/she shares his/her space with, can these situations be changed according to his/her preference? A score of '5' represents the response 'a lot' and a score of '0' represents the response 'not at all'. Scores for all three participants are displayed in Table 6. The table shows the discrepancy between the perceived levels of importance of a quality of life variable to the participant with the actual amount of choice and decision-making power he/she has over these variables. Where the number listed under 'Choice' and 'Change' is lower than the number listed under 'Importance', the participant's level of autonomy is less than equal to the perceived level of importance of that variable to him/ her. This is as appropriate measure for assessing the person- centeredness of post- transition planning because the individual should be central in all areas of his/ her life, especially those that are most important to him/her.

Margaret's scores reveal that for every domain perceived to be moderately (3) to highly (5) important to her she scored lower for 'Change' and 'Choice'. For example, staff perceive that it is very important to Margaret to have space for privacy (4) but the extent to which she makes her own decisions about space for privacy is very little (2). What is more, she does not have very much opportunity to change her privacy situation.

Heather's scores reveal that there is very little discrepancy between how important certain quality of life domains are to her and her level of choice and extent to which she can make changes to them. That means that her scores for perceived level of importance matched her scores for the amount of choice or ability to change aspects of that domain. For example, where she received a score of '4' ('quite a bit') on the perceived importance

of a domain she also received a score of '4' for amount of choice and ability to change that domain. Therefore, there was little discrepancy between how important an aspect of her life is to her and the amount of control she has over that domain. Exceptions include doing household work and looking after her physical health. Staff members perceive that her participation in housework is important to her but her ability to the amount of participation is low. In this case her score for perceived importance was higher than her score for choice or opportunity to make changes. Staff indicated that because she uses a wheelchair and has breathing difficulties she is not able to participate more in housework or engage in more physical activity.

For David, for 55% of the items perceived as moderately (3) to highly (5) important, his opportunity to change features about these domains was scored lower than the 'Importance' score. For example, David was given a score of '4' on importance of privacy and only a score of '1' for the extent to which he is able to make decisions about his space for privacy. For 64% of those same items he scored lower than the level of importance on the extent to which he makes his own decisions about those things. For example, in the section for Leisure Activities he scored '5' on the question, "How important to him is doing casual leisure activities?" but only a score of '3' on the corresponding question about the extent to which he makes his own decisions and for which there are opportunities to have more or different leisure activities

Finally, note the scores of '1' for all participants under 'Change' and 'Choice'. Results from this measure offer service providers and Facility Planners information on where effectors should be increased to support the person to have more autonomy over his/her own life.

A discrepancy analysis between scores on section M3 (Table 5) of the InterRAI-ID (2006) on the types of supports being received in the community and the quality of life domains (Table 6) perceived to be important to each participant revealed that no one is receiving support in areas perceived to be moderately to highly important to him/her. For example, David was given a score of '3' for learning new things, indicating a moderate level of importance. As reported above, the InterRAI-ID (2006) revealed that David was not receiving, or scheduled to receive, any skills training. Margaret's scores on the quality of life measure indicate that her physical health, hygiene, access to work/ school/ day programming, community access, and problem solving are very important to her. She is not receiving any type of formal supports in these areas.

None of the participants' current plans grew out of the original planning document according to the agency Administrators interviewed. Two consistent observations were made. First, all three supporting agencies had a different documentation style in terms of creating a planning document, none of which corresponded with the original plans. One agency Administrator, who is a former Facility Planner, reported that the plans were not easily incorporated into agencies' existing planning styles and so they were typically not incorporated. Rather, the agencies started over with their own plans. Another Administrator said that they wanted to learn about the person with a fresh perspective in the community; "we didn't want any preconceived notions."

Direct-care staff members were unaware of the existence and location of the original plan in all case. This is a significant observation because it is typically a direct-care staff member who takes the lead in writing personal care plans; each resident is assigned a lead-care provider who has the most intimate knowledge of his/her care and

supports received.

As described, a person-centered plan, as a living document, changes with the person. This requires that the plan be continually reviewed, revised, and updated according to the person's changing needs and goals. The planning process for all three participants deviated from this description. As reported, upon arrival at each of the participants' homes none of the direct-care staff members or home managers were aware that such a planning document existed, either in the form of the essential elements or transitional plan. It is important to note however, that the Executive Directors of all three agencies supporting the participants reported that they opted to implement and follow the planning procedures already in place at their respective agency. That is, according to the Administrators, practices and planning observed in the community did not stem from the personal plans written by the Facility Planners.

Although Margaret appears happy and confident in her environment the question asked is whether her surroundings, daily activities, and future programmed goals, if outlined, are person- centered. Again, person-centered planning differs from individualized planning in that it is not simply planned for the person but by the person herself/himself. In Margaret's case, although direct-care staff members are extremely caring and well- intentioned, her planning is more individualized than person-centered. The focus of the day program she attends is group activity. There is no individualized planning to support personal goals facilitating interaction or participation amongst the participants. It is possible to argue that Margaret is able to express her choice by being able to leave the group and engage in independent activity but these activities are limited to coloring and sticker books. Again, if these are preferred activities then it is positive

that she has access to them, but there is a significant lack of choice or selection. It was reported by group activity leaders at the day program that her engagement on the days of our observations was typical.

Finally, with respect to the extent of choice and options available to her regarding areas of quality of life perceived to be important to her, it is clear that Margaret has very little of either choice or options to make changes.

It should be noted that contained within David's current file are copies of Annual Support Plans. The plan consists of interview results with David's primary counselor and focus on many important aspects from a person-centered approach. For example, desired outcomes include that David stay connected to natural support networks, have intimate relationships, exercise his rights, decide when to share personal information, and choose where and with whom he lives. This is a standard support plan however, and these goals are not specific to David but rather a universal guide to planning for all residents. While it is positive that David's interests are being considered in the formal plan it is obvious both within individual goal summaries of the document and thorough observing and speaking with David that these goals are not being actualized. For example, one goal identified in his support plan and personally identified to us by David was to go out into the community more often, specifically, "bus" (David). It was noted, both within the plan and anecdotally by staff, that it is extremely difficult to secure transportation for him and that he leaves the complex grounds infrequently. Staff made note of the challenging and aggressive behavior David typically exhibits when they leave the community centre next door to walk back to his unit. His mood and affect were observed to change dramatically upon return to his suite where he was wheeled and left to sit in front of the

television for the next few hours.

Another goal identified in documents, originally dated almost one year prior to visit, is for David to reconnect with a special friend who used to live with David in the facility. According to documents and staff interviews this plan is still underway but not much progress had been made.

David was continually referred to as a very social person however he is not allowed to eat in the dining hall with the other residents because he frequently engages in loud vocalizations. Agency Administrators have worked hard to fight for this right for David but have been unsuccessful in their attempts. Currently, David eats his meals in his unit. He was observed to eat alone on all occasions during our visits. No formal or informal strategies are in place to focus on the inappropriate vocalizations or to teach him an appropriate alternative behavior that would support a plan for him to regain access to the dining hall.

What was unique about David's files was the formal written documentation of his goals. Goals were somewhat operationalized and assigned to specific staff to facilitate. There are also sections for timelines and results. Although it is not clear how these goals are to be actualized or if and when they are taking place on a daily or weekly basis, it does follow a person-centered approach that his goals are being considered and staff are making an attempt to document them on an ongoing basis. David's direct-care staff members are extremely caring and fond of him. From our observations David's day-to-day life is filled with friendly interactions from staff but very little activity or opportunity to try new things or experience life in the community. He makes very few decisions about his life.

The final purpose of this section was to identify themes correlated with the presence of absence of PCP in the community post- transition. To answer this question Administrators, Facility Planners, and direct-care staff were interviewed. The four themes presented here were identified from the above-described role-specific interviews (Griffiths, 2008) as well as direct observation.

1. An individual's participation was less where there was family involvement.

In the case of two participants, the family members acted as vocal advocates for their loved one. In both cases, the family was against the closure of the facilities and transition to community living, even actively fighting it. Now, some years later, both families are reported to be very happy with the current living situation of their family member. It was noted by the Facility Planners for both of these participants that the families directed each component of the transition process, reviewed each amendment to the written documents, were responsible for all the final decisions to be made, and held the Facility Planners accountable for every detail. It has been reported by the Facility Planners that the family members were the decision makers because the individuals for whom they were planning were not able to participate in the planning process. This does, however, conflict with the data that shows these individuals are both verbal and have good receptive communication skills. Also important to note, no time went into teaching choice making or preference identification (Facility Planner Interview).

In the case of the third participant, who moved into a home with her sister, no other family members are known to the agency. Her sister is not her advocate however, and is not a decision maker for her. This case was not typical of those leaving the facilities. Because she had visited her sister throughout the years in the community, the agency

already knew her and had 'secretly' been planning for her arrival for some time. They advocated for her to move in with her sister, on her behalf. The other woman living in the home also advocated for Heather. Therefore, her involvement in the process was likely encouraged by the receiving agency that was more involved in the early planning stages than other agencies for other cases.

No causal conclusions can be made from this however it raises an interesting question regarding the involvement of the family.

2. The individual's level of autonomy reflected the supporting agency's culture. As reported, Heather was the only participant who, according to our observations and staff interviews, was directly involved in the decision-making aspect of her life. What is more, she was the only one to make decisions. Although it is reasonable to say that her direct-care staff members interpret her communication, it is quite obvious by her facial expressions when staff interpret or misinterpret her responses. Where there is disagreement, staff members were observed to be quick to ask again, offer more options, and give her more time to respond.

Having met three levels of agency support personnel, from direct-care staff to the executive director, it is undeniable that the whole team working to support Heather is following the same mandate to support the person in *her* home. We had the opportunity to spend two full days at her home and also an evening in the community with her, her friends, and support staff. That evening, Heather and her friends, people from different group homes, community programs, and friends of friends, went to a local pub for dinner, drinks, and karaoke. We were with Heather that day as staff assisted her in getting ready for the evening. Of particular note was the process of helping her to pick out her outfit.

Heather, along with her sister, patiently waited as staff pulled out almost everything in her closet and waited for her reaction in order to put an outfit together. Heather selected everything from a matching scarf, shoes, and jewelry to hair accessories. By the end of the night the group had grown to over fifteen people as spouses and siblings of staff members, off duty staff, and friends of friends stopped by to visit. It is difficult to describe in words the atmosphere except to say that this was not an 'outing' for people in a group home. It was a night out for friends. In a sense, Heather and her wheelchair blended so that it was not about taking people with disabilities out in the community, it was simply friends getting together with friends. However, direct-care staff members pay close attention to Heather's reactions to people and places and consequently use those observations to shape future plans and offer these options to Heather and the other women with whom she lives. For example, when she meets someone she particularly appears to be happy with, staff immediately follow-up, arranging more get-togethers for her to see them again, if she wishes.

When the assessors requested copies of her support plans to review the Executive Director called the home and had the staff ask her if it was okay for him to release them to us. Again, one could argue that she may not understand the question or that she may not really answer clearly but the important point is that it is the culture within the agency that her home belongs to her and that staff are there to support her, her needs, and her wishes. It is not surprising then, that this home was the only residence that felt and appeared like a typical family home. The furniture was modern and matched the rest of the décor, pictures were hung with artistic flair, and there was a sense of calm that greeted you as you entered the spotless home. Along with that greeting were the two cats

that the women of that home have adopted. As contributing members of their community the women fostered these two cats and when it came time to return them the staff members reported that Heather was upset. Consistent with their views of the roles they play in her life, staff supported the women's wishes to keep the two cats as their pets. During our visits the cats were seen to make Heather smile, crawling up onto her wheelchair keeping her feet warm. As the supporting agency that most reflected a continued focus on person-centeredness they were continually asking the question, "what else can we do?" Or, "what haven't we done yet?" Staff drafted a long list of 'firsts' that Heather has experienced since moving into the community with her sister. Some of which they will do again, and some not. These experiences are all documented in her personal photo album.

3. In none of the three cases did the Facility Planner continue to be involved in the person's life for a period greater than approximately 3 months following the transition to the community although they viewed the plan as most useful.

The Facility Planner, the person who arguably put the most work into the written document and had the highest opinion of its utility, had very little contact with the individual after the move was completed. Follow- ups were frequently conducted informally by telephone.

All three agency Administrators reported that the plan did not guide their preparation or continued planning for the person. In one case, the Facility Planner commented, "it never went further than my desk." In one case, even the Facility Planner reported, "I never really looked at the plan following the move, it wasn't necessary".

4. The less clinical the written plan, that is, the more the plan reflected a person-centered

approach, the more person- centered we observed the person's life to be in the community.

The very nature of a person-centered approach implies that is may never be possible to definitively operationalize because in doing so it suggests that the process look similarly in every case. It was not surprising to see that all three plans differed in many ways but two of the plans were very similar in one major respect; clinical, deficit orientation. While information concerning the individuals' medical conditions and special support needs (i.e. bathtub or lift) are required to ensure the health and safety of the individual in his/her new home, program managers were quick to point out that all of this information could have been quickly and easily reported in a brief letter or email. "I didn't need to know that he had a cold one winter, forty years ago." Two agency Administrators commented that the plan depicted a very fragile person and did not reflect the person they met.

Heather's plan varied significantly from this description. It opens with her personal story, focusing not on her diagnoses, but instead on her personality, likes, and important relationships. Under Support Requirements, the Facility Planner wrote of the need for support teams to introduce her to new things, "this may mean sampling new experiences from which to make decisions about favored new ones." Another common theme in Heather's plan is that she be supported to meet new people who are not paid to be in her life and to frequent typical community venues. The final point in her plan is to ensure that her *sister* is involved in her life *according to each other's wishes*. This statement is reflective of the advocating being done by the agency on Heather's behalf for her to move to the community, be included in the planning process, and continue to live a life

she is directing.

Discussion

The purpose of this study was to evaluate the effectiveness of PCP in terms its successful application across people and settings, and over time. A review of the pre-transition experience, planning process, and written personal plan for three individuals with ID in Ontario revealed that with the exception of their medical history, the plans were generally not reflective of their pre-transition experience and limited by a deficit and clinical orientation.

Even though there is a reported lack of robust evidence conclusively linking person-centered approaches to better outcomes for people with ID it has become best practice and policy in Ontario (IFCO, 2007; Services and Support to Promote the Inclusion of Persons with Developmental Disabilities Act, 2008). However, there is evidence that personal planning is often not well connected to the real lives of the people it is designed to represent (Mercer, 2003). This is particularly true for people with more severe disabilities, as the benefits of a person-centered approach are not proportionately realized across all people with ID (Mercer, 2003; Reid & Green, 2002). Results demonstrate that there are multiple factors that contribute to a limited application of PCP including supporting agency values and the absence of ongoing involvement of an independent Facility Planner. The planning process for these individuals resulted in personal plans that were not well connected to the real lives of the people they were written to represent and instead produced deficit oriented clinical reports that were not favored or evaluated as beneficial by community agencies.

The MCSS Guiding Principles to Planning: Principles Observed

To investigate the effectiveness of person-centered planning in Ontario, a comparison of the planning process for three former residents of a Provincial institution was conducted with the MCSS Guiding Principles (2005). The MCSS Guiding Principles (2005) were established to assist Facility Planners in preparing an individual moving from a provincial institution. The document includes guidelines on individual, family, and community involvement, as well as the recommendation and identification of services. Reviews of the pre-transition experience and corresponding written personal plans were assessed according to the Guiding Principles (MCSS, 2005). The study revealed that in general, the plans met few of the principles. For the most part, plans reflected the voices of institution staff and family members; they were individualized rather than person- centered. Identified services were limited to existing supports. The identification of services beyond what is traditionally available is a key feature of person-centered planning in general (Medora & Ledger, 2005) and one that is often not implemented (Mercer, 2003). Mercer (2003) writes that this is often the case where service providers are focused on sustaining the system rather than supporting the person's choices, for various reasons. Margaret was the only participant who was directly involved in the planning process but this was initiated entirely by the receiving community agency who already had a long relationship established with Margaret in the community. In all three cases, planning involved existing processes, moving residents closer to a family member, and specialized mechanical supports were put in place where required. It was also found that the planning document did not continue to grow with the person and was consistently not referenced following, and sometimes during, the

transition. Plans were described as individualized, rather than person-centered by agency Administrators.

Medora and Ledger (2005) Key Characteristics of PCP: Characteristics Observed

A comparison using the plans was completed a second time, this time comparing the plans to the key characteristics of PCP identified by Medora and Ledger (2005). These characteristics include that it be chaired by a facilitator chosen by the individual, involve people identified as important by the individual, take place anywhere/ time and not be restricted to service-provider's schedules, owned by the individual, not governed by statutory requirements and start with an ideal world perspective rather than with current services. All three participants had a facilitator, or Facility Planner, although none was independent of service delivery and therefore not neutral. None of the participants was consulted consistently throughout the process or preparation of their personal plan. In all cases, the Facility Planner assigned to facilitate the process only met the individual two or three times. Those individuals formally included in the planning process were selected by the MCSS and provincial institution where the participant lived at the time. Family members were invited to participate and in all cases did to varying degrees, but they were listed as formal contributors to the process in one case only. Margaret and David's plans were written from a deficit perspective with very little description of their general abilities or specific skills relevant to community living. For example, Margaret had training in meal preparation, traffic signs, and small appliance use but this was not highlighted in her plan. The second differential characteristic is the attempt to include and mobilize the family *and* the wider community. In David's case, the immediate larger community he most regularly encounters is the senior citizen

community living in the same supported living community in which he now lives. The Administrator reported that the senior citizens from the home are from a "generation of exclusion" and that they are not used to the idea of people with disabilities living in the community (Agency Administrative Staff Interview). In David's case, community is not supportive of his inclusion. It does not appear that direct efforts were made to include these senior residents in the transition process to promote the inclusion of David into their day-to- day living once he moved in. In all cases the personal plans and transition plans were limited to existing services. In Heather's case, the agency supporting her and her sister have taken the lead in seeking out novel services to support Heather's active lifestyle. They do not limit her social and recreational activities to day programs but instead locate others options such as accessible cooking classes. Finally, in all cases, planning was governed by statutory requirements.

Post-transition: Person-Centered Planning Observed

The latter part of this study looked at the existence of a person-centered approach following the transition to the community and what characteristics were correlated with its presence or absence according to interviews with direct-care staff, agency administrative staff, and the Facility Planners. Four themes were identified to correlate with either the presence or absence of person-centered planning post-transition.

First, an individual's participation was less where there was family involvement. Future researchers might consider looking at the role family members play, in particular, with individuals with varying levels of communication abilities, and what responsibilities and conflicts this may present for the Facility Planner in balancing the directives of the family and the wishes of the individual in person-centered planning.

Second, the individual's level of autonomy reflected the supporting agency's values. These narratives reflect a lot of what was reported in Sanderson's (2002) report on person-centered teams. One of the characteristics described in Sanderson's (2002) research on the development of person-centered teams was changing the meetings to make them more accessible. This point relates back to the key characteristics identified by Medora and Ledger (2005) who noted that meetings should take place at a time and place that is most suitable to the individual and also to maximize attendance by others. One Facility Planner interviewed for this study commented that at planning meetings in the institution the person often "would act out, get a PRN, and be removed from the planning meeting." In situations like this, planning meetings likely proceeded in the person's absence. Again, Sanderson (2002) defines a person- centered *team* as one that "sees it's purpose as supporting people to achieve their desired lifestyle as part of their local community, and its members are characterized by their willingness to continually listen and learn and their high value on personal commitment and relationships with the people whom they support" (Sanderson, 2002, p.117). After visiting Heather's home it became clear that, in this instance, this had been achieved. Heather's home is not a place that belongs to the agency in which she was placed. Her home was purchased, built, and made to suit her. It is her home, and the staff members come to her home each to day help her to have the best day possible, everyday. Sanderson's research (2002), and our reported observations, present evidence to contradict a prevalent assumption that as long as there is a personal plan created it will be implemented. A planning team and supporting team mist also be a person-centered Team (Sanderson, 2002) or the plan might likely be limited in its application.

A final and noteworthy comment on this theme is that the occurrence of personal planning for the individual within the community was not identified as a goal of the Facility Initiative or the transition process. It seems odd to set up such a process in the planning phase without knowing whether the infrastructure in the existing system in the community is there to maintain it.

The third theme identified was that in none of the cases did the Facility Planner continue to be involved in the person's life for a period greater than approximately three months following the transition to the community although they viewed the plan as most useful. In other words, they had very little involvement with the individual or supporting community agency after the person left the institution but reported that the personal plans represented to individual well and that recommendations made within the plans were followed and implemented effectively. The IFCO published a paper in 2006 on the importance of independent planning and facilitation in Ontario. In it they define independent planning as having "*ongoing access* to a facilitator that listens deeply, provides, information, and assists with planning, network development, negotiation, relationship building, community development, based on the strengths, capacities, and self- determination of the person" (p.3, 2006). This is an alternative to agency driven services. The paper outlines two key elements of planning in need of transformation: direct individualized funding and ongoing independent planning and facilitation. The coalition makes the case for the need for ongoing access to independent Facility Planners highlighting that individuals will not be able to make the best use of his/her funding without ongoing facilitation support. "Within citizenship, increasingly seen as a key goal of community supports, individuals and their families require support to figure out how to

access community options that will enhance citizenship"" (IFCO, p. 4, 2006).

In the case of the Facility Initiative in Ontario, Facility Planners were hired and trained by the MCSS and so although not independent they did not represent community direct service agencies. Individual funding was also provided. Based upon these three cases, what appears missing from the model presented by the Coalition is the ongoing access to a Facility Planner.

In some communities in Ontario independent facilitators are available through a brokerage that acts solely on behalf of the individual with no direct connection to the service delivery system. Windsor-Essex Brokerage for Personal Supports in Windsor is a good example such a service. It was reported by an independent evaluator that those wanting an independent service such as this far outnumber the capacity of the MCSS facilitators who are available (IFCO, 2006). Future researchers might consider looking into the effect of providing more long-term, ongoing, assess to independent facilitators to people returning to the community, especially in the case of those who do not have a Facility Planner independent of any service agency to act in this capacity. We can speculate from this preliminary investigation that where a Facility Planner is available to continue to facilitate the planning process, planning in the community might be more person- centered. One key reason for this is because in every case the Facility Planner was the only person who reported any real value or use of the plan during and following the transition. Agency administrators reported that they did not use the plan other than for basic information about the person and that they did not use it for planning purposes after the person moved into the community. Direct-care staff members were unaware of the existence of the plan post transition.

Finally, it appears that the less clinical the written plan, that is, the more the plan reflected a person- centered approach, the more person- centered we observed the person's life to be in the community. Heather's personal plan followed many of the key characteristics of PCP (Medora & Ledger, 2005) and was also supported from a person-centered approach by the community agency. In this case, they the agency was involved in the planning process. There are many possible reasons why some plans took on a more clinical tone than others. Most obvious is the background of the team members and the Facility Planner assigned to write the plan. Also, influence from the family, notably motivated by concern for their family members care, directed Facility Planners' writings significantly, "they were worried that the community would not be able to support her and she would die."

An issue repeatedly encountered when exploring the degree of involvement of the individual in his/her transition and community living plan was that the person was not able to participate because he/she did not understand the situation or could not communicate his/her goals or wishes. These observations are presumably accepted because of the nature of the participant's diagnosis of ID. However, one Facility Planner revealed that this was the case for many people, " the biggest challenge was getting them to understand that they do have a right and a choice, *even when cognitively able.* Naturally, they would never open up because they were never given options. They had no experience in speaking up for themselves." Since this was generally the case for people with varying cognitive and communication abilities it does not seem that the argument for the lack of participation of these participants is sufficient. Knowing this, the tight timelines imposed by the MCSS, the reports from Facility Planners regarding the

ability of some individuals to communicate functionally, and research demonstrating inaccurate identification of preferences by support personnel (Reid and Green, 2002), future planning might do well to place greater emphasis on the voice of the individual in the planning process including consideration to the non-verbal communication of preferences through actions and reactions and the use of technologies for systematically teaching and evaluating choice making. This however means allocating sufficient time and resources to ensure that the individual is truly included.

Support for the process of others making choices for people with ID who have never had the experience of making choices for themselves as a default strategy is carried over from this process in traditional service planning especially when considering the magnitude of a choice of neighborhood or if he/ she would like a job (Reid & Green, 2002). It has been questioned whether he/she would know how to make these choices or even understand that he/she had options. Many of the former residents have rarely been asked to indicate their preferences on choices of lesser magnitude. In the case of these three individuals the argument was made that the next best person, the person who knew them the longest or most intimately, would be in the most appropriate position to make these choices on behalf of the individual. However, as Reid and Green (2002) remind their readers "reliance on support personnel for these purposes contradicts results from empirical research in this area." As noted, their investigations have shown that preferences identified by care providers typically do not accurately reflect the actual preferences of the individual with ID when assessed using systematic preference assessments (Reid & Green, 2002). These types of behavioural assessments allow for the identification of preferences made by the individual and are especially relevant for those

with more profound ID. Still, this systematic choice making is not likely to be an established skill. Mercer argues that part of "helping people exercise their rights involves teaching decision-making skills" (p.18, 2003). Knowing that the technology exists to teach decision-making and to assess preferences, the process should involve more than asking someone who knows the person well.

Summary

A significant body of evidence is lacking to definitively conclude that person-centered approaches result in better outcomes for the individual they are designed to represent. This is partly due to the individualized nature of PCP. Behavior analysts such as Holburn and his colleagues continue to define and narrows ways to scientifically evaluate PCP. However, it is not likely that randomized clinical trails and gold-standard research designs will ever be able to incorporate the person- centered nature of this process. In Holburn et al.'s (2004) controlled study, better quality of life outcomes were reported for individuals with person-centered plans compared to a matched traditional planning group. Therefore, preliminary, well controlled, research is beginning to show evidence in support of personal approaches to planning

The authors of the Signature Paper (2007) point out that evaluation, learning, and sharing of information are an integral part of the success of this process and one of the necessary transformations in developmental service systems. It is also through these methods that the individual clinician, Facility Planner, or team can contribute to the growing body of literature (IFCO, 2007). Following the scientist-practitioner model, individuals working in this area should adopt an applied research framework and begin to define, measure, and share their work with greater frequency and in various outlets.

Using single-case deigns allows for more control, something not possible in the qualitative research that dominates the PCP literature. Considering that PCP is being written into law, mandated by governments, and funded with millions of dollars more collaboration and ongoing research is still needed to establish an evidence base for this practice. Finally, those choosing to adopt and implement PCP need to do so with the awareness of the lack of conclusive evidence. Ongoing measurement against defined procedures and goals is necessary.

Limitations

The current study is limited in several ways. First, as a case study no causal conclusions can be drawn from the reported correlations. The small number of participants limits making generalizations from conclusions presented here. Additionally, this is a retrospective study. Information collected was based on events occurring up to three years before our interviews and so the accuracy of responses depends on the recall of informants. Finally, the researchers spent only two days with each participant. The stories presented here are written based on the information collected through extensive file reviews and multiple interviews. Every effort was made to represent the informant's information as accurately as possible and without bias.

Future Research

Result of the effectiveness of PCP identified here will need to be paired with further rigorous effectiveness studies. As Felce (2004) noted, the identification of conditions under which the implementation of PCP is possible without degradation of the process is required for policy to be effective and for its impact to remain significant. This study has identified numerous variables that should be evaluated further in future

effectiveness research. For example, the type and degree of family involvement and it's affect on PCP should be considered, especially for individuals with ID and communication challenges. Future research should also focus on the affect of the community agency's values and person-centered teams on PCP in the community. Finally, the affect of ongoing access to independent Facility Planners should be considered.

Conclusion

In conclusion, one of the Administrators of a community agency currently supporting an individual who moved from one of the final institutions to close in Ontario shared a caution: "Don't accept, out of a facility, life is great. In doing so we are creating a new institution." After being welcomed into some of the most intimate spaces of these people's lives it appears particularly relevant to share these powerful words.

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Table 1

Government-operated Institutions for People with a Developmental Disability

Facility	Location	Year Opened	Year Closed
Huronia Regional Centre	Orillia	1876	2009
Oxford Regional Centre	Woodstock	1905	1997
D'Arcy Place	Cobourg	1920	1996
Durham Centre	Whitby	1950s	1987
Pine Ridge Centre	Aurora	1950	1984/85
Rideau Regional Centre	Smiths Falls	1951	2009
Southwestern Regional Centre	Chatham-Kent	1961	2008
Muskoka Centre	Gravenhurst	1963	1994
Midwestern Regional Centre	Palmerston	1965	1998
Adult Occupational Centre	Edgar	1966	1999
Prince Edward Heights	Picton	1970	1999
Northwestern Regional Centre	Thunder Bay	1974	1994
Bluewater Centre	Goderich	1976	1984/85
Nipissing Regional Centre	North Bay	1975	1977/78
St. Thomas Adult Rehabilitation and Training Centre (S.T.A.R.T. Centre)	St. Thomas	1975	1984/85
St. Lawrence Regional Centre	Brockville	1975	1984/85

Note. Retrieved from http://www.mcss.gov.on.ca/en/dshistory/firstInstitution/list_institutions.aspx

Table 2

Participant Demographic Information

	Nature of ID	Age- time of study	Age- left home	# yrs lived in institution	Time lived in communing-time of study
Margaret	Down's Syndrome	57 yrs 6 months	5 yrs 4 months	50 yrs 5 months	1 year 9 months
Heather	Cerebral Palsy	55 yrs 4 months	6 yrs 9 months	43 yrs 9 months	4 yrs 11 months
David	Unspecified	62 years 9 months	13 years 9 months	46 yrs 7 months	2 years 5 months

Note. Numbers rounded to the nearest month.

Table 3

MCSS Guiding Principles Criteria Met

	Heather	Margaret	David
Process will involve the resident, family, placement facilitators, & supporting community agency	Heather was not involved	Margaret was somewhat involved	David was not involved
There will be a comprehensive plan tailored to each individual	Plan is *individualized*	Plan is *individualized*	Plan is *individualized*
Individuals will have opportunity & support to make informed decisions about their lives	No	Yes	No
Individual's decisions about location & type of arrangements given primary consideration	No	Yes	No
Individual's decisions about maintenance of friendships and family ties will be given primary consideration	No	Yes	No
Planning for supports & services will be flexible and respectful of cultural, language, religious beliefs and lifestyle choices	No	Yes	No
Whenever possible, individuals will have the opportunity to live close to their families and friends	Yes	Yes	Yes
Wishes of the individual and their family will be balanced with available resources	Wishes of the family considered.	Heather's wishes considered.	Family wishes considered.
Where individual does not have family or friends independent of the service system, neutral 3rd party will participate in the process	N/A	No	N/A
Planning will involve existing community processes	Yes	Yes	Yes
Individual should have opportunity to live, work, and participate with members of the community	Moderate	A lot	Minimal
Supports should include existing community services	Yes	Yes	Yes
Supports will promote physical & emotional well being in settings that foster healthy independent living	Yes	Yes	No
Individuals will not leave facility until arrangements are in place	No. Medical files not received by community physician before medical appointment as promised to family	Yes, arrangements prepared well in advance	Yes, move was delayed as suite was not ready
Specialized supports & services as required will be provided or developed	Yes	Yes	Yes

Table 4

Characteristics of PCP (Medora & Ledger, 2005) and Relationship to Individuals in the Study

	Margaret	Heather	David
Chaired by the person or facilitator	Yes	Yes	Yes
The person is consulted about all planning	No	No	No
Involving the most important people, selected by the individual	No	No	No
Takes place when & where most suitable for the person	No	No	No
Owned by the person	No	Yes	No
Starts with ideal world not current services	No	Yes	No
Brings about change, more choice, control	No	Yes	No
Takes place a s frequently as required	No	No	No
Not governed by statutory requirements	No	No	No
Facilitator is not a service provider, care manager, or team manager.	No	No	No

Note. Adapted from Medora & Ledger (2005).

Table 5

Focus of Supports in the Community

	Margaret	Heather	David
Self-care training (dressing, hygiene)	0	0	0
Community Skills Training (shopping)	0	0	0
Social skills training (etiquette, interpersonal skills)	0	0	0
Cognitive Skills (help with reading letters, numbers, signs)	0	0	0
Education on special topics (sexuality, safety)	0	0	0
Behaviour Management (increase functionally equivalent behaviours)	0	0	0
Sensory stimulation programs (music therapy, aromatherapy)	0	3	4

Table 6

Comparison of Quality of Life Questionnaire scores (University of Toronto, 1997)

	Margaret			Heather			David		
	Importance	Choice	Change	Importance	Choice	Change	Importance	Choice	Change
Health	**5**	2	5	**5**	0	5	2	2	3
Food	**5**	4	3	**5**	4	4	3	3	5
Hygiene	**5**	4	4	5	5	5	1	4	2
Where he/she lives	**5**	2	4	5	5	5	1	1	1
Privacy	**5**	2	3	3	5	5	**4**	1	2
Neighbor-Hood	1	1	4	5	5	5	**2**	1	2
Significant Other	1	1	1	5	5	5	2	3	2
Family	**5**	3	4	5	5	5	**4**	3	4
Friends	**4**	4	3	5	5	5	**4**	3	3
Access to training	1	1	1	2	5	2	1	3	4
Access to work	1	1	1	1	5	5	1	3	2
Going out	**4**	3	3	5	5	5	4	4	4
Working/ School	**4**	2	5	**5**	5	2	1	4	1
Chores	1	5	4	**3**	5	1	1	3	4
Looking after others	2	3	2	5	5	5	**3**	2	2
Socializing	**4**	2	3	5	5	5	**5**	5	4
Hobbies	**5**	3	4	5	5	5	**3**	3	2
Leisure activities	2	4	4	5	5	5	**5**	5	3
Learning	2	2	3	5	5	5	3	3	3
Solving problems	**4**	3	3	5	5	5	2	2	3
Changes in life	**4**	2	3	5	5	5	3	3	3

Note. Boldface and underlined numbers represent domains where 'Change' and/or 'Choice' scores are *lower* than 'Importance' scores.

Appendix A

CASE STUDY RECORD FORMS: HISTORY QUESTIONNAIRE DERIVED FROM ARCHIVES AND INTERVIEWS

STEP 1: INTERVIEWING THE INDIVIDUAL AND SIGNIFICANT CAREGIVERS AND REIVEWING ALL DOCUMENTATION.

(Develop from review of the files including all past evaluations/ programs and fill in blanks with observations and staff interviews)

1. **Where has this person lived previously? Why were moves precipitated?**

2. **Create a timeline of the person's behavioral/psychiatric history and significant life events (Provide dates to show correlations).**

Behavioral/Psychiatric History

/_____/_____/_____/_____/_____

Significant Life Events

/_____/_____/_____/_____/_____

STEP II: BIOMEDICAL/ PSYCHIATRIC ASPECTS

1. **Does the individual have any of the following:**
   - ( ) ***known syndromes***
   - ( ) ***medical conditions***
   - ( ) ***ongoing medical problems***
   - ( ) ***psychiatric diagnoses***

   Specify any and all of the above:

2. **What is the health status of the person and has the health of the individual changed recently? How? When?**

3. **Has the person been hospitalized within the past 5 years and if so for what reason?**

4. **Does the person experience problems in any of the following:**
   ( ) activity level or energy_____
   ( ) socialization_____
   ( ) interest in previous activities_____
   ( ) eating_____ Note any special dietary needs_____
   ( ) skills_____
   ( ) bowel or bladder _____
   ( ) irritability_____
   ( )sleep_____ Describe

   If so, please describe when did the problem start and how?

5. Does the behavior:
( ) come out of the blue
( ) show no predictable pattern
( ) occur with hallucinations or delusions
( ) occur with repetitive verbal behavior
( ) occur with specific repetitive physical behavior

If so, please describe:

6. List present medications/ dosages and reason for prescription? Have medications for the individual changed recently? How and when?

7. Could the medications in any way contribute in isolation or in combination to the any problems the person may be experiencing? If so how?

8. Develop a timeline of the medical/ medication history to the behavioral/psychiatric changes (provide dates to show correlations)

Medical History/Medication Changes

/_____/_____/_____/_____/____

Behavioral/Psychiatric Changes

/_____/_____/_____/_____/____

9. What medical/psychiatric considerations must be taken into account when the person is transferred? (support/ specialists/ personal vulnerabilities/ setting events/ staff training etc.)

STEP III: PSYCHOLOGICAL ASPECTS

1. **Describe the strengths that this individual presents and how they contribute to the person's ability to adapt and enjoy life?**

2. **a) How does the person communicate?**
( ) words, ( ) sentences, ( ) sign language, ( ) picture boards. ( ) blissymbols. ( ) gestures, ( ) behaviors

   Describe:

   b) Does the person have:
   - ***i. ( ) an accessible means to communicate***
   - ***ii. ( )communication that results in desired attention from others***
   - ***iii. ( ) communication that results in desired outcomes***
   - ***iv. ( ) other***

   c) Does the person make his/her physical needs known? How?

   d) Does the person make feelings known? How?

   e) Does the person communicate preferences and choices? How?

   f) Can the person indicate need for help? How?

   g) Does *the person express needs behaviourally? How?*

3. **Does the individual experience difficulty in dealing with some situations, how is it manifested?**

4. **What skills does the person use to relax/calm?**

5. **What coping mechanisms help him/ her to cope?**

6. **Have there been habilitative programmes in place for the individual to increase independence, adaptation or as replacement for challenging behaviours? If so what are they, were they effective and are they still advised?**

7. **What habilitative elements should be present in the new setting? (i.e. teaching communication or coping skills etc.)**

STEP IV: SOCIOCULUTRAL FACTORS

1.

a) **Are there situations where the individual experiences more or less satisfaction/ dissatisfaction in the day?**

b) **Are there times of the day when the person experiences more or less satisfaction/ dissatisfaction?**

2. Are any of these situations associated with dissatisfaction for the person:

( ) if there is excessive stimulation
( ) following requests or directives
( ) following a demand to do a task
( ) when doing difficult/challenging tasks
( ) when it is noisy
( ) when there is excessive activity
( ) when it is crowded
( ) when teased/provoked by others
( ) in the presence of specific people
( ) in specific settings/activities
( ) at specific times of the day
( ) when situations are unfamiliar
( ) when situations are frightening
( ) when changing to a less desired activity
( ) when in a prolonging activity
( ) at low activity time
( ) at low reinforcement time
( ) when reinforcement is diverted elsewhere
( ) when others are reinforced for their behavior
( ) when a preferred/desired activity is ending
( ) in presence of preferred people
( ) if communication is ignored or request denied
( ) if stopped/interrupted from a desired activity
( ) if praised

Describe in more detail those situations that apply.

3. What interactional / environmental changes might create a situation more suited to the needs of the individual?

( ) reducing/altering approach to or number demands
( ) changing activities or timing of activities
( ) providing choice of activities
( ) leave alone
( ) increased time for personal comfort needs
( ) changes in meals, toileting, rest routines

( ) reduce demands at vulnerable times
( ) letting the person do anything desired
( ) providing choices of activities
( ) increased personal support time
( ) increased access to reinforcers
( ) greater access to desired activities & materials throughout the day
( ) increased opportunity to engage in stimulating activities
( ) increased/partial participation in more activates
( ) more access to materials
( ) more access to leisure activities or hobbies
( ) other

Describe in more detail:

4. How does the person react:
( ) when hungry, thirsty, tired, ill
( ) before or during menses
( ) when afraid, tense or anxious
( ) just before or after seizures

For each item checked, describe in detail:

5. **Does the person appear more satisfied:**
( ) when alone
( ) independent of who is present
( ) in routine/familiar/less active situations
( ) when in unchallenging situations

To those checked above, describe each:

6. **Does the person participate in the community? What activities are valued by the individual? What activities present challenges? Are there specific community social situations that are problematic? How are safety issues assured when in the community?**

7. **Does the person have known hobbies/ interests/ sporting activities? If you allowed this individual to do whatever he/she wanted what would it be?**

8. **Does the person show spiritual needs (participation in religious activities/ observation of special days or holidays)? How are these best met?**

STEP V. BEHAVIOURAL CONCERNS

---

1. **What are the behavioural concerns if any? If none proceed to step VI.**

2. **Why is it seen as a problem?**
    a. *( ) occurs too frequently (how frequent?)*_____
    b. *( ) occurs for long periods of time (duration?)*_____
    c. *( ) is very intense (specify)*_____
    d. *( ) is not appropriate to place, time, people etc. (specify)*_____
    e. *( ) causes damage/health risk to individual or others (specify)*_____
    f. *( ) causes damage to property (specify)*_____
    g. *( ) interferes with the individual's opportunity to socialize, learn or be involved in*
        i. *Desired activities (specify)*_____
    h. *( ) is disruptive to others (specify)*_____

3. **Expand on any of the above:**

4. **Does the behavior:**
    a. *( ) occur in isolation*
    b. *( ) cluster with other behaviors*
    c. *( ) have early signs that signal you it is going occur*
    d. *( ) occur constantly or does it change over time (i.e. cycle)*
    e. *( ) appear to have changed recently*

5. **Describe any of the above you checked:**

6. **Has this behavior recently changed and if so how?**

7. **Have there been other changes apparent in the individual at this time? (i.e., physical appearance, interests, sleep, appetite, energy, responses to people or the environment)?**
8. **What possible functions does the behavior serve:**

Does the behavior serve to:	**Specific functions**	**Possible Hypotheses**
allow the individual to avoid/escape/ remove or delay an undesired	*( ) attention, interactions* *( ) activity or task* *( ) demands*	*Negative Reinforcement*

	( ) setting events (i.e., noise/lights/crowds) *( ) other*	
Gain desired	*( )attention, counselling, physical intervention, reprimands, individual time* *( ) tangible outcomes (i.e., food/object)* *( ) change in activity* *( ) continence of an activity*	*Positive Reinforcement*
Provide	*( ) interruptions to discomfort* *( ) relief from discomfort* *( ) physical needs*	*Negative Reinforcement*
Provide	*( ) sensory stimulation*	*Positive Reinforcement*
Communicate	*( ) a desire to escape and avoid a situation/ person/event* *( ) pain, anxiety, fear, hunger, or discomfort* *( ) desire for attention, change of activity, change in reinforcement* *( ) no intention to communicate*	*Negative Reinforcement* *Negative Reinforcement* *Positive Reinforcement*

9.

a) Currently what reaction does the behavior appear to most often receive? Describe:

b) Does the behavior result in gaining the person:

i. ( ) accelerated attention
ii. ( ) physical contact
iii. ( ) gaining access to desired possessions
iv. ( ) change of activity or access to an activity
v. ( ) individual supervision
vi. ( ) counselling by staff'
vii. ( ) access to preferred people
viii. ( ) help or comfort
ix. ( ) a tangible item
x. ( ) is scolded or reprimanded
xi. *( ) intervene to interrupt the behavior*

c) **Does the behavior result in changing/reducing some situations such as:**
   - *i. ( ) activity is discontinued*
   - *ii. ( ) interaction is stopped*
   - *iii. ( ) person is removed from situation or time out*
   - *iv. ( ) others removed from situation*
   - *v. ( ) activity is delayed*
   - *vi. ( ) demands are reduced*
   - *vii. ( ) noise is reduced*

d) **Was the response to the behavior consistent across time and people? If not describe.**

e) **Did the observations support the hypotheses regarding the interviews with caregivers? If so what is the motivation(s) for the behavior(s)?**

STEP VI. COMPARISON OF HISTORY AND INTERVIEW DATA WITH ESSENTIAL PLAN

	Elements that should be considered in Transitional Planning to ensure positive quality of life	*Elements that are in the Essential Plan*	*Discrepancy*
Medical/ Psychiatric (including health/ mobility/ fitness/ nutrition)			
Socio-Environmental a) Social (meaningful relationships) b) Physical "at home in environment"/ safety/ privacy) c) Programmatic (purposeful meaningful daily activities) d) Leisure (activitiies/ hobbies) d) Spirtual (values/ celebrations) e) Community Inclusion			
Psychological (initiating positive behaviour/ sense of self/coping skills/ personal expression and choices and opportunity for learning and change)			
Behavioural (minimization of distress)			

***Further* considerations for placement observations**

Appendix B

INTERVIEW QUESTIONS: FRONT LINE STAFF (Community)

Case Number:
Date:
Period of Interview: Post/ 3 month/6 month/12 month

Hi My name is _____ and I am the research assistant who will be following _____(NAME) through the first year of his/her move to evaluate how the process is going for him/her. We appreciate that you have agreed to be part of this evaluation and share your experiences with us. This is the first/ second/ third/fourth or fifth call in what will be five contacts this year. If at any time you wish to not continue to help us with the evaluation, please let us know. However we truly appreciate your input and feel it will teach us a great deal about what is happening and what needs to happen in the closure process

A. Adjustment/adaptation to the transition

1. How well is the individual adapting to the new situation?
2. Would you say the person has accepted the transition?
3. If so how long did it take for the transition to be accepted?
4. Has the person developed strong relationships with staff? Can you give me some examples?
5. Has the person developed strong relationships with peers? Can you give me some examples?

B. Setting and Supports

6. How appropriate do you feel this setting is for the individual? Why?
7. What is the current ratio of staff to this individual during the day (:); at night(:), in the community (:)?
8. Do you think the staffing is sufficient to meet the person's needs?
9. What type of training have the staff received in the past few months to support the needs of this individual? Is it sufficient and appropriate? Is there need for more training?

10. Does the person see (name professional) and if so how often? If these re new or if there are changes in professional support why were services added or deleted?

Physician	
Dentist	
I Therapist	
Psychiatrist	
Physiotherapist	
Occupational Therapist	
Speech/ Communication	
Social Worker	
Neurologist	
Psychologist	
Other	

11. Are there services that are needed but not available?
12. Would you say the support services are sufficient and appropriate for the person?

C. Daily Routines

13. What time of day does the person awake on weekdays___ weekends____Does the person awoken or does he/she awake themselves?

14. What time is breakfast on weekdays_____weekends_____? What time is lunch on weekdays _____ weekends ? . What time is dinner on weekdays_____ weekends ?

15. Does the person help in meal preparation? How?

16. How is his/her appetite? Are there any challenges at mealtime?

17. What time is bedtime on weekdays_____ weekends_____? Who initiates bedtime?

18. When does the person bathe? Daily, every other day, weekly. Is bath at a scheduled time or initiated by the individual?

19. How are the person's sleeping patterns? Does he/she awake during the night or is woken by staff? Why?

D. Activities and Community Inclusion

20. Are you pleased with the amount and appropriateness of meaningful/personally fulfilling things the person has to do each day?

21. Are these new interests?

22. Does the individual exercise daily?

23. What daily household activities does the person participate?

24. Does the person have a day programme? Where is it? Is it individualized or participation in a group activity? Do you think it is a good match for the individual?

25. Has the person shown increase in independence since moving to your agency or since our last visit? Can you give examples?

26. I will name some activities and ask you to say if the person does these things frequently (monthly), sometimes (less than once a month) or never.

	Frequently (at least once a month)	Sometimes or rarely (less than once a month)	Never
Dining in a restaurant			
Receiving visits from friends			
Receiving visits from relatives			
Visiting friends (outside the home)			
Visiting relatives			
Telephone calls to or from family			
Telephone calls to or from friends			
Socialization with peers			
Going to place of worship			
Going to a movie			
Going shopping			
Going on a holiday			

Attending a concert or play			
Watching a sporting event			
Visiting a social club			
Visiting a park or going for a walk			
Going to a barber/hairdresser			
Are there other activities the person does that I have not mentioned?			

27. How is the person actively <u>included</u> in the community? What leisure and community activities does the person regularly participate?

28. Has the individual had contacts with neighbourhood or general community?. Have these contacts been positive or negative?

29. Has family and friend contact has changed since the move or last evaluation?

30. Since placement or our last evaluation have family or friends helped the individual relative to advocacy, support/advice, or emotional support?

31. Has the individual's new setting affected the relationships with family and friends in the past few months? Can you give some examples?

32. Has the individual gone with family or friends on an overnight stay since the transition or last evaluation?

33. Has the individual shared meals with family or friends since the transition?

E. Changes since Transition

32. What choices about his/her own day has the person been making? Is it increasing?

33. Has the person experienced a change in medical status/ health? Please explain. Has there been hospitalization since transition or last evaluation? Have there been medication changes or diagnostic changes?

34. Has the person experienced behavioural challenges since transition or since last evaluation? Are the challenges greater or less than expected from the Essential Elements Plan or previous period?

35. How are they being managed? Are the strategies working?

36. Has the individual required police contact? If so please elaborate.

37. What are the biggest changes in the individual since transition/ last evaluation?

    a. Health or mental health
    b. Interests
    c. Adaptive skills
    d. Self-care
    e. Communication
    f. Social Skills
    g. Other… please give examples

F. Quality of Life

38 Tell me about the individual's quality of life today.
What do you think is the most important factors responsibility for the quality of life? Would you recommend things to improve his or her quality of life? Are there problems in accessing additional resources and if so why?

41. What new plans and goals do you have for this person today that you did not have previously?

40. Is there anything else you want to add to help us understand the person?

Summary

41. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix C

INTERVIEW QUESTIONS: AGENCY ADMINISTRATIVE STAFF

Case Number:

Date:
Period of Interview: Post/ 3 month/6 month/12 month

Post

1. Did you feel prepared to accept this person into the programme?
2. What supports were you able to arrange to have in place when the person moved?
3. What adaptations have you made to the setting to accommodate this person? Have you been given supports to enable these adaptations to occur?
4. What specialized staff and training has been done? Are you being funded appropriately for this?
5. Has the planning been individualized? If so how?
6. How has the family been involved? How often will you communicate with them after the transfer?
7. How confident are you that you will be able to successfully support this individual?
8. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?
9. Do you feel the Essential Elements Plan captured the needs of the person?
10. How does your transitional plan align with the Essential Elements Plan? How will it be actualized? Where if anywhere will it differ?

3MONTH/6 MONTHS/ 12 MONTHS

1. How do you think this person is doing in the programme you designed? Tell me about it.

2. What supports are in place for the person currently? Are they sufficient? Are they accessible? Are their additional supports needed? Were some supports recommended but not needed. If so why?

3. How have the adaptations have you made to the setting to accommodate this person worked out?
4. Are you finding there were other adaptations that were needed or that some of the adaptations you made were unnecessary?

5. Do you feel the staffing is still sufficient? Do staff need additional training? Have they received any?

6. How has the individualized planning paid off or has it?

7. How has the family been involved? How often will you communicate with them?

8. How confident are you now that you will be able to successfully support this individual?

9. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?

10. Do you feel the Essential Elements Plan still captures the needs of the person?

11. How does your current plan align with the Essential Elements Plan? Where if anywhere does it now differ?

12. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix D

INTERVIEW QUESTIONS: FACILITY PLANNERS

Case Number:
Date:
Period of Interview: Pre/ Post/ 3 month/6 month/12 month

POST

1. Did you feel that the Essential Elements plan was ready for the person to move into the community? Are you confident that the implementation plan based on the Essential Elements Plan is in place?

2. What supports were arranged for when the person moved? Are there supports that should be in place but were not accessible? Why?

3. What adaptations have been made to the setting to accommodate this person? Has the agency been given supports to enable these adaptations to occur?

4. What specialized staff and training has been done? Are they being funded appropriately for this staffing ratio and training?

5. Has the planning been individualized? If so how?

6. How has the family been involved? How often will you communicate with them after the transfer?

7. How confident are you that the chosen agency will be able to successfully support this individual?

8. Does he or she pose any challenges that are unusual for this agency? If so what are these challenges? How do you see the agency overcoming them?

9. Do you feel the Essential Elements Plan captures the needs of the person?

10. How does the transitional plan align with the Essential Elements Plan? How will it be actualized? Where if anywhere will it differ?

/3MONTH/6 MONTH/ 12 MONTH

1. How do you think this person is doing in the community programme that has been designed? Tell me about it.

2. What supports are in place for the person currently? Are they sufficient? Are they accessible? Are their additional supports needed? Were some supports recommended but not needed. If so why?

3. How have the adaptations to the setting to accommodate this person worked out?
4. Are you finding there were other adaptations that were needed or that some of the adaptations you made were unnecessary?
5. Do you feel the staffing is still sufficient? Do staff need additional training? Have they received any?

6. How has the individualized planning paid off or has it?

7. How has the family been involved? How often will you communicate with them?

8. How confident are you now that you will be able to successfully support this individual?

9. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?

10. Do you feel the Essential Elements Plan still captures the needs of the person?

11. How does your current plan align with the Essential Elements Plan? Where if anywhere does it now differ?

12. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix E

INTERVIEW QUESTIONS: FAMILY

Note: questions will be personalized to use the name of the person and some questions may only be asked during the first interview as some placement situations will not change in most cases.

Case Number:
Date:
Period of Interview: Post/ 3 month/6 month/12 month

Hi My name is _____ and I am the research assistant who will be following your family member through the first year of his/her move to evaluate how the process is going for him/her. We appreciate that you have agreed to be part of this evaluation and share your experiences with us. This is the first/ second/ third/fourth or fifth call in what will be five contacts this year. If at any time you wish to not continue to help us with the evaluation, please let us know. However we truly appreciate your input and feel it will teach us a great deal about what is happening and what needs to happen in the closure process.

Basic Questions:

How are you feeling about the placement at this time?

Has your family member adapted well to the new physical environment?

Has your family member adapted well to living in a smaller setting?

How are his/her relationships with the staff? With others living in the home?

Would you say the location is a good fit for your family member?

Are you satisfied that the design of the home is appropriate for your family member?

Are you satisfied with the staffing arrangements?

Does your family member have the level of professional/ medical supports recommended?

Are you pleased with the quality and access to needed professional/ medical supports?

Is there good communication with the new agency?

Are you geographically closer to your family member?

How often are you able to visit? Call? Have your family member visit?

What word describes the quality of life of your family member now?

Is anything happening that you did not anticipate?

If you have a concern you wish us to bring to the attention of the Ministry on your behalf regarding your family member then let me know and my supervisor, Dr. Griffiths will be asked to call you so she can gain consent to share information with the Ministry. Otherwise the information you have provided will be used anonymously as collective information only.
SHOULD FAMILIES INDICATE THEYWISH US TO CONTACT THE MINISTRY ON THEIR BEHALF THE FOLLOWING WILL BE SENT TO THEM.
FAMILY REQUEST AND CONSENT TO FOLLOW-UP WITH THE MINISTRY OF COMMUNITY AND SOCIAL SERVICES

Dear Family Member
I understand you have a concern/ comment that you feel we should follow-up with the Ministry
By filling in the following you are giving me permission to share with the Ministry of Community and Social Services the following concern about your family member. You may send that concern/comment together or separate from this survey if you wish to at the address below.
Sincerely Dr. Dorothy Griffiths Project Lead

Name of Person

Name of Agency where s/he currently resides

The concern I would like you to bring to the attention of the Ministry is: *(Please, feel free to expand on back or on separate sheet to fully explain your concern)*

I understand that by signing below I am requesting and authorizing Dr. Griffiths to share this information with the Ministry of Community and Social Services on behalf of my family and my family member.

Signature of family member

Relationship

Date

Dr. Dorothy Griffiths, Co-Principal Investigator on the Facility Initiative Evaluation and Associate Dean, Faculty of Social Sciences, Brock University, St. Catharines Ontario L2S 3A1

Appendix F

CASE STUDY CONSENTS AGENCY ADMINISTRATION

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac

Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction
The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research
The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research
If you agree to participate in this study, you will be asked to be interviewed four times throughout the year. The purpose of the interviews is to maintain an ongoing story from many perspectives of the transition experience of the individual you have accepted into your agency. The questions we will ask you

relate to your perspective on the process, for example how has the transition worked for the individual, the challenges that have been faced, the availability of appropriate supports, and how well the planning process prepared the agency to support the individual.

The Research Assistants will visit your agency 4 times throughout their first year. Each visit will take approximately 2 days however we will interview you for only ½ hr to 1 hr out of that time. The Research Assistants will be interviewing other individuals, including staff while on duty, observing the individual, conducting random video taping of the person engaged in an array of activities, collecting data and reviewing the individual's file and reports. The time with your staff members will take approximately 1 day each visit however some of this time will be spent in observations with the staff member as they conduct their day.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. However each agency that participates and completes the requirements of the case study will receive an educational voucher. The voucher will be equal to a 50% discount on for four staff members of the organization to attend an educational event offered through the international dual diagnosis certificate programme (a $1500 value) summer 20010 or 11 or 15 free admissions to a training event offered by the centre for applied disability studies or a combination thereof.

Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law, such as in cases of suspected neglect or abuse. No information that you share with us will used in any way except as collective data; the Ministry will not be privy to your comments.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the topic projects or theses for students studying in the Masters of Applied Disability Studies.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Agency Administrators

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

I however have some exceptions to this consent: The exceptions are:

X_____	_____	____
Signature of Agency Administrator	Name (printed)	Date
_____	_____	____
Signature of Investigator	Name (printed)	Date

Appendix G

CASE STUDY CONSENTS AGENCY STAFF MEMBERS

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction
The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research
The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

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Description of the Research
If you agree to participate in this study, you will be asked to be interviewed to complete several measures regarding the wellbeing and quality of life of the individual and to participate with our research assistants as they walk through the life of the individual. We will be asking you questions about the general wellbeing and functioning of the individual such as about the supports, health, activities and choices the person makes. The Research Assistants will be occasionally taking video samples of a typical day in the life of the individual. This is being done to see the types of activities and interactions the person participates in on a daily basis. *These tapes will be analyzed and maintained in a*

confidential location in our laboratories. No video tape of you will be ever used except for the purpose described above without your expressed permission.

The Research Assistants will visit the person and meet with you 4 times throughout their first year during the course of your working day. Each visit will take approximately 2 days. Although the full two days will not be spent solely with you or the individual, we ask that you be available for the full two days although only 1 day cumulatively will likely require your time. The Research Assistants will be interviewing other individuals and will be reviewing the individual's file and reports.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information. Nothing that you tell us will be shared with anyone from your agency, unless you disclose a situation of neglect or abuse in which case we are compelled to report this.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. However each agency that participates and completes the requirements of the case study will receive an educational voucher. The voucher will be equal to a 50% discount on for four staff members of the organization to attend an educational event offered through the international dual diagnosis certificate programme (a $1500 value) summer 20010 or 11 or 15 free admissions to a training event offered by the centre for applied disability studies or a combination thereof. It is the agencies responsibility to decide how the voucher will be distributed.

Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law. For example, the researchers would have an obligation to report abuse should it be observed or reported during the course of our research.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records

and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the subject of projects and theses for students in the Masters of Applied Disability Studies programme.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671,
e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca

For Agency staff members

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix H

CASE STUDY CONSENTS Family Members

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year following the transition, your family member has been selected as one of those case studies. This study will provide an important look at the individual stories of those individuals who are affected by the Facility Initiative and the perspectives of their families.

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Description of the Research

If you agree to participate in this study, you will be asked to be interviewed four times throughout the year following placement then 3, 6 and 12 months following the first visit). The purpose of the interviews is to maintain an ongoing story from the perspective of the transition experience on your family mernber and you. You will be asked about the transitional process and how you feel your family member is doing and your satisfaction with the supports that are available. Each interview will take approximately ½ hr to 1 hr out of your time. The Research Assistants will also be interviewing other individuals, visiting your family member and speaking with him/her, collecting data and reviewing the individual's file and reports.

Some of the people moving from the facility to the community are able to answer questions about their experiences. We would like to ask the following questions of your family member if the person can and agrees to speak with us. The questions we would ask prior to the move are: Do you know where you are moving to? Have you visited the new place yet? Did you like it? Tell me about it. Have you met the people who will help you there? Did you like them? What do you think it will it be like? Do you think this is a good place to be going? How do you feel about leaving_____? What will change in your new place?

Then at 3,6,and 12 months we would revisit and ask: . *Would you like to talk to me for a little while about how you feel about your new home?* Will you show me around your house? Show me the things you like about this new place? What do you like about living here? Who are they people you like to be with? What do you get to do in the day? Is this a good way to spend your day? Are there some things you don't like as much about this place?

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you or your family member feel uncomfortable, we can skip any question that you or your family member do not want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of your family member and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law, such as in cases of suspected abuse or neglect. The Ministry nor the agencies involved will not have access to your comments or those of your family member.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:

In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the subject of projects and theses for students studying in the Masters of Applied Disability Studies.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no negative effect on you or your family member. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

EFFECTIVENESS OF PERSONAL PLANNING

For Family MEMBERS

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study and to have my family member as a participant in this study as discussed in the consent guidelines.

I will be given a signed copy of the consent form and guidelines.

X_____ _____ ____
Signature of Family Name Date

Appendix I

CASE STUDY CONSENTS Regional Facility Planners

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction

The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

.

Description of the Research

If you agree to participate in this study, you will be asked to be interviewed three times throughout the year. The purpose of the interviews is to maintain an ongoing story from many perspectives of the transition experience of the individual you have helped place in the community. Each interview will take approximately 1 hr out of your time. The questions we will ask are about the planning process for this individual and how well it has worked to create a smooth transition, Other questions might include the access to supports and challenges in the transitional process. The Research Assistants will be interviewing other

individuals, observing the individual, collecting data and reviewing the individual's file and reports.

We will attempt to find a time during your work day that is convenient for our interview.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law. No information you share with us will be shared with the staff or agencies involved or with the Ministry unless you inform us of neglect or abuse, which we are obligated to report to the authorities.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the topic of projects or theses for students studying in the Applied Disability Programme.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:

Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca

For Regional Facility Planners

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

X_____	_____	____
Signature of Regional Facility Planner	Name	Date
_____	_____	____
Signature of Investigator	Name (printed)	Date